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ABSTRACT

This collection of three issues focuses on problem solving skills for children with deaf-blindness, the history and change in the education of children who are deaf-blind since the rubella epidemic of the 1960's, and early identification of infants who are deaf-blind. Specific articles include: (1) "Research to Practice Focus on: Hands-on Problem-Solving Skills for Children with Deaf-Blindness" (Charity Rowland and others); (2) "Transdisciplinary Activity-Based Assessments for Students Who Are Deaf-Blind" (Sandi Baker and Jennifer Grisham-Brown); (3) "Communication and Culture: How They Relate to Service Development and Advocacy for People Who Are Deaf-Blind: A Report on a Presentation by Dr. Harlan Lane at the Hilton/Perkins National Conference on Deafblindness" (Peggy Malloy); (4) "National Transition Study of Youth Who Are Deaf-Blind: A Family Perspective" (Jerry G. Petroff); (5) "The New IDEA: Updates and Resources" (Gail Leslie); (6) "Katlyn's Hope: A Not-for-Profit Corporation Established To Assist in the Education of Deaf-Blind Children" (Shari Willis); (7) "History and Change in the Education of Children Who Are Deaf-Blind since the Rubella Epidemic of the 1960s: Influence of Methods Developed in the Netherlands" (J. van Dijk and Catherine Nelson); (8) "Ways To Incorporate Physical Fitness into the Lives of Individuals Who Are Deaf-Blind" (Lauren J. Lieberman and Jessica Taule); (9) "Benjamin's Bar Mitzvah" (Nancy Sall and others); (10) "Early Identification of Infants Who Are Deaf-Blind: A Systematic Approach for Early Interventionists" (Deborah Chen); (11) "Research to Practice Focus: FM Systems for Children Who Are Deaf-Blind" (Barbara Franklin); (12) "The Universality of the Usher Experience" (Ilene Miner); (13) "My Continuing Journey with Usher Syndrome" (Winnie Tunison); and (14) "Notes from AADB:

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Sharing My Perspectives" (Harry C. Anderson). (Some articles contain references.) (CR)

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Deaf-Blind Perspectives

Volume 5, Issue 1 Fall 1997

Research to Practice
Focus on:
Hands-On Problem Solving Skills for Children with Deaf-Blindness

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U.S. Department of Education Grant Number H025D30024

What are Problem Solving-Skills?

We are constantly engaged in problem solving, whether it be getting out of a traffic jam, programming the VCR, or doing a crossword puzzle. The solution to any problem, concrete or abstract, requires certain basic mental skills like memory, planning, and reasoning. Many children who are deaf-blind, however, because of limited visual and auditory information, are not able to independently solve the typical problems which arise in their physical worlds such as opening a door, going around an obstacle, learning how a new toy works, or searching for a lost object. Children who do not experience success in these situations are often unwilling to tackle new problems and can become passive or unmotivated to explore their environments. They may even "learn" to become helpless and overly dependent on others.

Charity Rowland and Phillip Schweigert have designed a project to help children who are deaf-blind develop the skills to solve real-life problems. Dr. Rowland and Mr. Schweigert recognized that the solutions to many typical problems are well within the grasp of most children. Consider the example of a ball rolling under a chair. There are several possible solutions, such as using a stick to get at the ball, asking someone for help, or going behind the chair to gain access. Each solution requires cognitive skills such as recognizing obstacles, anticipating the whereabouts of the ball, engaging in a systematic search, or perceiving other objects as tools. But Dr. Rowland and Mr. Schweigert believed that the traditional ways of learning cognitive skills—sorting shapes or counting objects, for example—would not prepare these children to become better problem solvers. Their approach was to observe, instead, how children deal with "everyday" problems, identify what skills were naturally involved, and then think of new and enjoyable learning activities that could be implemented in school and at home.

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How can we assess these skills?

The project developed two instruments to assess problem-solving skills. Dr. Rowland and Mr. Schweigert saw the need to develop "user-friendly" tools to help parents and teachers understand their children's abilities. One is the "Home Inventory of Problem Solving Skills," or HIPSS, which was designed for parents. The HIPSS lists 33 important problem-solving skills, such as handling, exploring, avoiding, assembling, finding, using, or activating household objects. Parents are asked to think about what their child does with objects around the home in everyday activities (e.g., using toothbrush, cooking, brushing the dog, putting toys away) and check off the

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statement that best describes their child's ability in the skill area. Three of such skill areas are illustrated in Figure 1. The other assessment tool, designed for educators, is the "School Inventory of Problem Solving Skills," or SIPSS. The SIPSS is an inventory of the same 33 skill areas, but emphasizes those problem-solving situations that might arise in the school and classroom (e.g., looking for sandwich, turning on the computer, locating classroom, putting Legos together). On the SIPSS, space is provided to indicate in which classroom activities each skill is demonstrated and whether opportunities are provided for the student to use each skill.

Although both the HIPSS and SIPSS can be scored, there are far more important outcomes. These instruments

- Document that all children who are deaf-blind exhibit at least some basic problem-solving skills. These skills are usually overlooked in more traditional forms of assessment.
- Highlight skills that are involved in typical home and classroom routines and provide multiple examples of each skill. No special tasks, materials, or instruments are required.
- Help parents and teachers think of everyday activities as natural opportunities for children to gain experience and confidence in solving problems.
- Suggest the materials and situations that can promote greater independence in problem solving skills.
- Point to the similarities and differences in the problem-solving opportunities a child might have between home and school.

How Can We Promote Problem-Solving?

Once the assessment of a child's problem-solving skills is completed, intervention programs for school and home can be designed. In this project, the HIPSS and/or the SIPSS were completed for 105 different children with deaf-blindness. For 68 of those children, both the HIPSS and the SIPSS were completed. The children were from the states of Washington, Oregon, New York, Texas, Vermont, Maryland, Indiana, and Massachusetts. Within the state of Oregon, Dr. Rowland and Mr. Schweigert worked with teachers, therapists, and parents to identify and create active learning experiences to promote problem-solving skills. The SIPSS was often used to generate an inventory of the opportunities that were occurring already for other students in the classroom to use each skill. This information was then used to suggest ways to address specific skills for the targeted student.

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Ways to Gain Access to Objects

Instructions: Check the ONE statement that best describes your child's skill. If none apply leave blank.

Skills, General Description and Examples

A. MAKES DETOUR

Moves self around an obstacle in order to get desired object that is behind it. Child must move **away** from the object in order to get around the obstacle.

- Moves **around** table to get to object on the other side of it.
- A ball is on the other side of the fence. Child moves **away** from the ball to get around the fence in order to get the ball.

- ❑ Can do at least one of these examples and usually does it independently when given the opportunity.
- ❑ Can do something else that I think demonstrates this skill and usually does it independently when given the opportunity. Please describe below.
- ❑ Clearly understands what needs to be done, but physical limitations prevent my child from doing this independently. However, with some physical assistance or adaptation s/he can do this and usually does so when given the opportunity. Please describe below.

_____

_____

B. REMOVES BARRIER

Removes an obstacle that stands between child desired object.

- Pushes away chair that stands between self and object.
- Opens shower curtain to look in shower.
- Removes towel to find toy that is underneath it.
- Pulls mom's hands from face when playing peek-a-boo.
- Opens curtain or door to look outside.

- ❑ Can do at least one of these examples and usually does it independently when given the opportunity.
- ❑ Can do something else that I think demonstrates this skill and usually does it independently when given the opportunity. Please describe below.
- ❑ Clearly understands what needs to be done, but physical limitations prevent my child from doing this independently. However, with some physical assistance or adaptation s/he can do this and usually does so when given the opportunity. Please describe below.

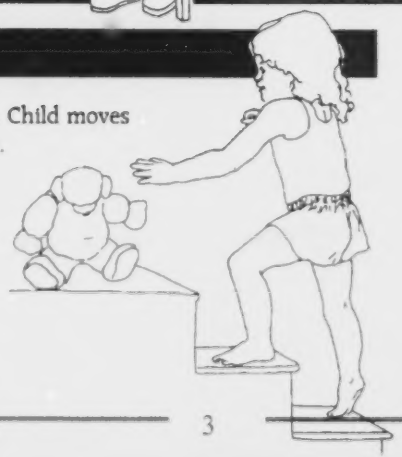
_____

_____

C. GOES OVER OR UNDER BARRIER

Goes over or under a barrier to get something on the other side. Child moves toward object, but must climb over or go under barrier to get it.

- Crawls under table to get desired object that has rolled under it.
- Climbs onto chair to get cup on table.
- Climbs stairs to get toy on landing.
- Crawls under blanket to get toy.
- Crawls under bed to find desired object.



- ❑ Can do at least one of these examples and usually does it independently when given the opportunity.
- ❑ Can do something else that I think demonstrates this skill and usually does it independently when given the opportunity. Please describe below.
- ❑ Clearly understands what needs to be done, but physical limitations prevent my child from doing this independently. However, with some physical assistance or adaptation s/he can do this and usually does so when given the opportunity. Please describe below.

_____

_____

5

Figure 1

6

Problem-solving skills give children independence and the ability to adapt to different situations, materials, persons, and environments, and allow them to participate more meaningfully in activities of everyday life. These skills promote self-confidence and motivation. Through their research, Dr. Rowland and Mr. Schweigert have identified some effective ways to promote these important skills in normal daily routines:

- We tend to do things for our children to "help them" or save time. Whenever possible, give children the opportunities to perform or actively participate in even the most mundane tasks (e.g., wiping face with cloth, searching for coat, unwrapping candy, putting used napkin in trash). Inherent in these tasks are basic but essential problem-solving skills. Just as important, each time a child solves a problem, no matter how simple, the child's motivation and self-confidence are raised.
- We can think about how familiar items (e.g., comb, milk container, liquid soap dispenser, light switch, music cassette box, candy wrapper) can be used to teach exploration, access to, and use of objects. Children who gain experience with a greater variety of items that provide opportunities to use problems-solving skills benefit from increased cognitive opportunities and, often, communicative opportunities.
- Assessment of problem-solving skills might best be done in the context of everyday classroom and home activities by persons who are familiar with the child.
- If we think about basic routines (e.g., holding a hair brush the right way, inserting a straw into a cup, or turning a door knob) as problems to be solved, the opportunities for helping a child gain cognitive skills are almost limitless.
- Even though a child may learn a particular skill with particular materials (e.g., opening the lid of a container), one cannot presume that the child will "generalize" that skill to other situations and materials. It is, therefore, important to provide many "generalization opportunities." That is, one should teach the same skill in different routines. Taking a cookie out of a jar, a toy out of a toy chest, and a sandwich out of a bag are examples of the same basic skill, but knowing how to do one does not necessarily mean that the child who is deaf-blind knows how to do the other.
- It is very important that parents and teachers communicate with each other about what skills they observe in the child. Disparities might exist in the opportunities a child may have to engage in problem-solving at home as opposed to in school. Look at these environments to see how opportunities for problem solving may or may not be present. Notice what problem-solving skill areas have or have not been observed. Consider all the ways to expand, not necessarily duplicate, the problem-solving experiences a child that a child may face.
- We can observe other children to see how they manipulate and explore materials to discover tips about how others approach or take advantage of problem-solving opportunities. These tips can suggest ideas for designing active learning experiences for the child who is deaf-blind.
- We can make the "problem" to be solved increasingly challenging for the child. Having mastered the basic skill (e.g., walking to the slide from 2 feet away), the child can draw upon his or her experience to attempt the same task under different or more difficult conditions (e.g., locating the slide from a greater distance or from a different starting point).

For more information about this project, or to obtain copies of the most recent versions of the HIPSS and SIPSS, contact

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Dr. Rowland and Mr. Schweigert are continuing to study the validity and utility of these assessment instruments in a current project on creating classroom environments that nurture independence for children who are deaf-blind.

Charity Rowland and Phillip Schweigert provided the written and interview information for this article, which was prepared by Harvey Mar as part of DB-LINK's Research-to-Practice Initiative.

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Transdisciplinary Activity-Based Assessments for Students who are Deaf-Blind

Sandi Baker, M.Ed
and
Jennifer Grisham-Brown, Ed.D.

Student assessment has long been a source of frustration for professionals who work with students who are deaf-blind. The University of Kentucky Deafblind Project currently provides technical assistance to local school districts to provide transdisciplinary activity-based assessments for students on the Kentucky Deafblind Census. In transdisciplinary assessment, members from a variety of disciplines work together to evaluate and plan educational programs and to transfer information across disciplines.

The use of a transdisciplinary play-based, assessment approach with young children (6 months to 6 years) has been documented by Linder (1993). For program planning purposes, the UK Deafblind Project adapted this model to assess school-aged students who are deaf-blind. For many students in Kentucky this type of assessment has also been used to fulfill the requirements of the 3-year evaluation. In this approach, students participate in preferred, age-appropriate activities and are assessed by a transdisciplinary team of professionals and family members who "share a common philosophy and goals." (Schwartz & McBride, 1995).

Most traditional assessment tools used with students who are deaf-blind are standardized and deficit-based, and they evaluate student skills in nonfunctional, isolated settings. As a result, information gained from these assessments is generally not useful for program planning. Transdisciplinary assessments, on the other hand, focus on student strengths, active family involvement in the entire process, and assessment in natural environments while the students are participating in age-appropriate activities. Because many areas of development are interrelated, this type of assessment can lead to a more holistic view of the student. (Linder, 1993).

Results of this type of student assessment include fully integrated, nondiscipline-specific reports and recommendations, functional, activity-based IFSP/IEP/ITPs, and educational programs that are relevant and meaningful.

The role of the professional coordinating the transdisciplinary assessment is multifaceted. As soon as you receive the request from the school district, consider doing the following:

Establish your role EARLY. Clarify what you can and cannot do to facilitate the assessment (see below for coordinating the logistics).

Establish the lines of communication. Clarify with whom you will communicate and who will contact and contract with the team members.

Work with the school committee to identify areas of need. This will help you identify which disciplines will be involved in the assessment.

Establish the purpose of the assessment (Is it for a 3-year evaluation?).

Provide a list of professionals. It is essential to maintain the integrity of the assessment process. You will need to provide the decision-making committee with a list of professionals who understand this kind of assessment process and who have experience with students who are deafblind.

Logistics

As part of the preliminary work, you will also need to concern yourself with the logistics of the assessment.

Schedule time, date, and location. This should be convenient for the family, as well as familiar to the student.

Provide school district with information. The school district will need to know how to contact the professionals who will be involved with the assessment and also what their fees will be.

The following steps will help you design and implement the transdisciplinary activity-based assessment:

Select the assessment activity. To identify possible assessment activities, consider family and student preferences as well as family and school schedules and activities. For example, you may choose making a snack as a viable assessment activity.

Identify all materials to be used. Consider how age-appropriate these materials are, as well as any adaptations or modifications that may be needed. These may include consideration of color/contrast/size of materials, adaptive switches, if necessary, placement of materials, and the student's mode of communication.

Determine which skills you wish to assess. Ask what skills the student needs to have in order to participate in this activity. You may obtain information by observing someone perform the activity. You may also examine the skills that are listed on standardized (discipline-specific) assessment tools in the following categories: fine motor, gross motor, vision, auditory/hearing, social, cognitive, communicative, orientation and mobility. (See Sample Assessment: "Making a Cracker Snack and Orange Juice Shake.")

Conduct a task analysis. Ask what the facilitator must do to make sure all skills are addressed during the assessment.

Identify personnel. These may include the following:

Activity facilitator: Someone who knows the student. This is the primary person to interact with the student during assessment.

Observing team members: Professionals from various disciplines who will provide the facilitator with input as needed or requested. For example, the speech therapist may ask the facilitator to withhold materials to determine if the student will make requests; the physical therapist may ask the facilitator to position the student a certain way.

Parent facilitator: This person, the most important member of the team, should be available to give input, validate the information, and assist in facilitating assessment activities as needed.

If, following the assessment, more information is needed, you may wish to conduct an additional assessment activity with the student. On the other hand, it may be more helpful to have a different team member conduct the original activity. If still more information is needed, you may wish to conduct a more traditional, isolated assessment with the student.

Once the assessment is completed, you will wish to do the following to generate a report:

Problem-solve with the assessment team to come up with recommendations that are nondiscipline specific and that include necessary adaptations and modifications to curriculum, activities, and materials.

Collect a one-page summary from each team member.

Submit the integrated report to the school district.

For further information regarding assessment activities and developing assessment protocol, contact the Kentucky Deafblind Project at (606) 257-7909.

Sample Assessment: Making Cracker Snack and Orange Juice Shake

Materials: crackers, cheese, other topping(s), orange juice, milk, vanilla, ice cubes, blender, cups, plates, mixing spoon, measuring spoons/cups, napkins, apron, adaptive switch, control unit

Skill categories:

Fine Motor:

Grasp materials to make snack

Type of grasp: _____

Bring hands to midline during cooking

Turn/open lid on cheese, milk, vanilla

Pour from container

Orange juice, milk, ice cubes, vanilla into blender

Orange juice shake into cups

Open packages (e.g. box/bag of crackers, orange juice)

Locate visual target and place item on target

Other:

Gross Motor:

Move to kitchen area

From: _____

Stand while participating in activity

Sit in chair independently while doing activity

Other:

Vision:

Attend to large/small objects in visual field

Visually focus on person

Visually follow a moving person

Look toward light source

Visually locate objects

Track objects horizontally/vertically

Scan objects

Watch things happen in surroundings

Visually locate, then pick up dropped objects

Attempt to secure objects beyond reach

Consistently recognize/discriminate (food) objects

Exhibit depth perception

Other:

Auditory/Hearing:

Be aware of voices/environmental sounds

Discriminate voices/sounds

Attach meaning to sounds/words

Localize to sound/voice

Imitate sound/word

Attend and respond to simple requests

Laugh out loud

Other:

Adaptive:

Put on apron prior to activity

Other:

Social:

Greet others

Take turns

Share

Initiate, maintain, terminate social contact

Imitate teacher or peer making snack

Other:

Cognitive:

Attend to activity

Problem solve:

If cup or plate are too full, gets another

Other:

Cause/Effect

Switch turns on blender

Label or identify utensils

Plate, cup, napkin, blender, switch, spoon

Other:

Sequence steps to:

Make orange juice shake

Make cracker snack

Understand use of objects

References

Linder, T.W. (1993). Transdisciplinary Play-based assessment: a functional approach to working with young children. Baltimore: Paul H. Brookes.

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Communication and Culture: How They Relate to Service Development and Advocacy for People Who Are Deaf-Blind

A Report on a Presentation by Dr. Harlan Lane at the Hilton/Perkins National Conference On Deafblindness

Peggy Malloy

The human brain has a remarkable ability to adapt to the absence or loss of sight and hearing. This adaptability and its implications for the development of language, education, and ways of interacting with the world for people who are deaf-blind was the theme of a speech given by Dr. Harlan Lane at the Hilton/Perkins National Conference On Deafblindness held in Washington, D.C., last June. Dr. Lane, a psychologist and linguist, has written extensively about deaf culture and language.

This article summarizes some of the key points addressed by Dr. Lane, but focuses primarily on his principal theme about the importance of helping children who are deaf-blind learn and develop by surrounding them with people, language, educational programs, and environments that match their unique sensory abilities. An understanding of how the sensory abilities of people who are deaf-blind differ from those of people who are hearing-sighted and the underlying neurological basis for this can help parents, deaf-blind adults, and others who work with deaf-blind children create environments that will nurture each child, promote language development and learning, and support social and emotional needs. As part of this, Dr. Lane suggests that deaf-blind children be educated in specialized rather than mainstream environments. He also sug-

gests the creation of opportunities for deaf-blind children to form connections with deaf-blind adults.

How the Brain Adapts

Dr. Lane began his address by stating that, just as evolution gives species the ability to adapt to changing environments over millennia, it gives us as individuals the ability to adapt to our own environments within our lifetimes. The ability of the human brain to adjust to or compensate for what he called "different sensory configurations" such as deafness, blindness, or deaf-blindness is one such adaptation. This adaptive ability is greatest early in life, but can also occur in adulthood.

The way the brain compensates for the absence or loss of a sense is by enhancing the function of the remaining senses. This adaptation is called "cortical plasticity." Dr. Lane described two mechanisms by which cortical plasticity can occur. The first mechanism is increased activity in areas of the brain devoted to a particular sense when that sense receives increased stimulation. Braille readers and string players, for example, show "evidence of increased cortical representation of the fingers."

The second way in which the brain adapts is by allocating areas of the brain normally devoted to one sense to other remaining senses. This is called "functional reallocation." In people who are born deaf or become deaf later in life, the brain allows areas of the auditory cortex normally used for hearing to be reallocated to visual processing, giving deaf people enhanced visual abilities. Likewise, in people who are born blind or become blind later in life, areas of the visual cortex that normally process vision may be reallocated to tactile sensitivity.

People who are...deaf-blind communicate and interact with the world through channels that are different from those of people who are hearing and sighted.

Thanks to cortical plasticity, our brains adapt to make use of the senses we have available to us. People who are deaf or blind or deaf-blind communicate and interact with the world through channels that are different from those of people who are hearing and sighted. Therefore, says Dr. Lane, input from the environment in the form of language, social interactions, and education should suit their own abilities rather than those of hearing-sighted people. He calls this "modality appropriate-stimulation," a topic he discussed in some depth, particularly as it relates to deaf-blind children and their developmental and educational needs. The ideal environment for the deaf-blind child is one that uses language, child-rearing strategies, educational methods, and social interactions that match that child's unique sensory abilities.

Examples of Modality-Appropriate Stimulation

According to Dr. Lane, only people and communities who have a particular sensory configuration themselves are able to create or evolve the types of modality appropriate-stimulation—language, culture, and other environmental resources—that suit their particular sensory abilities best. Hearing-sighted people can't do this because they have not adapted to alternate sensory configurations. For this reason it is the deaf-blind community, in his opinion, which is in the best position to develop the resources that deaf-blind children need.

Dr. Lane gave examples from the deaf community which illustrate the importance of modality-appropriate stimulation and can be used as a model by the deaf-blind community.

The first example of modality appropriate stimulation that evolved within the deaf community is the development of American Sign Language of the Deaf (ASL). According to Dr. Lane, "There's no clearer evidence of the need for modality-appropriate stimulation than the sustained failure over four centuries in teaching those born deaf to speak." Speech training generally fails, he said, with children who were born deaf or who became deaf early in life because it is difficult to teach an auditory language to a visual person. "One may acquire oral language naturally, using hearing, or one may acquire a visual language naturally, using vision, but one cannot acquire oral language naturally, using vision."

ASL is a visual language that is acquired naturally by deaf children who are exposed to it. It has qualities and characteristics that make it perfectly suited for visual communication. The hand shapes and movements, for example, are highly visible and succinct and make use of space and facial expressions. ASL could never have been invented by hearing people, because they do not have the same visual abilities as deaf people.

A second example of modality-appropriate stimulation is the entire visually oriented environment that deaf children of deaf parents are raised in. Deaf chil-

dren raised by deaf parents are exposed not only to a language that matches their own sensory abilities, but to child-rearing techniques and visual modifications in the home that make it possible for the child to reach developmental milestones of language, social interaction, and education on a normal schedule.

Creating Modality-Appropriate Environments and Education for Children Who Are Deaf-Blind

According to Dr. Lane, deaf-blind adults can offer the same advantages to deaf-blind children that deaf adults offer to deaf children. The deaf-blind community, he said, can provide "a model for living, a range of strategies, culture, validation, peer and social relationships, recreation, and roles to fill." The deaf-blind community can also provide access to employment opportunities, instruction in Braille and other skills, advocacy, and links to support services and interpreters.

In order for the deaf-blind community to be a major resource in the development of deaf-blind children, two things must happen. First, continued growth of deaf-blind culture must be encouraged. According to Dr. Lane, deaf culture and language have flourished because deaf people have connected with each other in communities and residential schools. Dr. Lane believes that deaf-blind people need to form more of these types of connections.

Second, in order for the deaf-blind community to be a major resource in the development of deaf-blind children, increased opportunities for contact between the deaf-blind child and the deaf-blind community must be created. Dr. Lane gave several suggestions for how to bring this about. In areas with active deaf-blind communities, he said, community leaders should collaborate with educators and other people involved in the lives of deaf-blind children to establish programs that bring deaf-blind children and adults together. In areas where there is no deaf-blind community the child can benefit from contact with either the deaf community or the blind community. Children who communicate in English or another spoken language will probably fit in best with the blind community. Children who communicate in sign language or have not yet learned a language are more likely to benefit by contact with the deaf community.

Dr. Lane believes that educational programs in specialized settings that surround the deaf-blind child with other deaf-blind children and with deaf-blind adults, rather than with hearing-sighted children, are more likely to promote the deaf-blind child's development. Examples of specialized settings include residential schools, magnet schools, special day programs, and camps. In these settings, deaf-blind children will interact not only with other deaf-blind individuals, but also with specially trained professionals who, " if they are not deaf-blind themselves, nevertheless have the knowledge and experience to present language, environment and social interactions" in ways that match the child's own sensory abilities. The opportunity to learn according to their own capabilities, apart from the mainstream, will make it possible for them to rejoin the mainstream later on.

> *"We must place the deaf-blind child apart from the mainstream among people who know how to provide modality-appropriate stimulation in order that the child may rejoin the mainstream as a competent participant. In this way, we honor his or her deep rights as a human being. We must not confuse the appearance of rights with the rights themselves. When we affirm with the universal declaration of human rights that all people are born equal in human dignity and rights, do we mean that deaf-blind children have the right to be treated in exactly the same way as sighted-hearing children, or do we mean they have the right to have their distinct indentity valued? Does every child have a right to go to the local school or the right to an education? Does every child have a right to speech or a right to language?"*

We must not confuse the appearance of rights with the rights themselves.

The message of Dr. Lane's speech was that we should respect and embrace the sensory differences of deaf-blind children. An understanding of how the brain finds new pathways when particular senses are unavailable can help people who are involved in the lives of deaf-blind children recognize and respond to their unique needs.

Although this article has focused primarily on issues relating to children, Dr. Lane also talked about how the brain adapts to sensory loss later in life and the impact this has on adults. The keynote speaker at the conference, Dr. Oliver Sacks, a well-known neurologist and writer, spoke on related themes. The texts of both speeches will be available as part of the general conference proceedings which have not yet been published. To be placed on a waiting list for information about the conference proceedings, call the Hilton/Perkins office at (617) 972-7228.

National Transition Study of Youth who are Deaf-Blind: A Family Perspective

Jerry G. Petroff

During the past 40 years, through the efforts of the judicial process, significant gains have been realized in creating equal educational opportunity for all students, including those with disabilities. However, recent studies of students with disabilities have showed substantial gaps between typical students and students with disabilities regarding post-school status in employment, post secondary education, and residential independence.

In response to these circumstances, Congress requested that the U.S. Department of Education conduct a national study of secondary special education students (ages 13- 21) to determine how they fare with regard to education, employment, and independent living. The study, entitled the National Longitudinal Transition Study (NLTS), was conducted several years ago by Stanford Research Institute International (Menlo Park, CA) and may be considered the largest efficacy study ever conducted on special education. The NLTS included students who represented all 11 federal disability categories, which included "deaf-blindness." However, due to the low incidence of this disability category, limited conclusions were made regarding students who are deaf-blind. In addition, there were other extenuating circumstances that appear to have influenced the ability to yield information from the NLTS for youth who are deaf-blind.

Youth identified as deaf-blind, besides being a low-incidence population, are a heterogeneous group that is difficult to describe. Although annual census data on the number of children and youth is maintained, it is confined to demographic information that includes etiology, disability types, and current living and educational settings. More detailed information is necessary to more accurately describe the specific nature of those identified as deaf-blind. In addition, since census data does not go beyond the point when a student leaves the educational system, there is no information on the post-school status of these individuals. It is this difficult to describe the experiences of this group, evaluate the effectiveness of our current educational programs, describe post-school life, or establish further directions for new research.

NTAC, (The National Technical Assisstance Consortium on Children and Youth Who are Deaf-Blind) in an attempt to fill this need, in collaboration with this author, has initiated a national study to gather descriptive information regarding youth who are deaf-blind, their educational experiences, and post-school status and needs as reported by parents. This study is titled "National Transition Study of Youth who are Deaf-Blind, Perspectives of the Family." With the assistance of each of the state deaf-blind projects, each parent of a student identified as deaf-blind who left school in June, 1996 has been asked to complete a detailed survey. The comprehensive survey requests information regarding the student, his or her secondary school experiences and his or her current post-school status. This research initiative will represent the first comprehensive national follow-up study on youth who are deaf-blind. Establishing parameters of the population by working backwards from describing the people within this category will give us clear markers for identifications. The results of the National Transition Study of Youth who are Deaf-blind are expected to be reported and available sometime in the late fall, 1997. For additional information, you may contact:

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DB-LINK

The New IDEA: Updates and Resources

Gail Leslie

The changes that come with the implementation of the new IDEA will affect many areas of special education programming and service delivery. Because many of the provisions of the bill became effective at the June 4, 1997 signing, teachers, parents, and administrators begin the new school year with substantial changes already in effect. In the coming months, the federal government will be working with states to further define how the statutory language translates to policies and procedures. Other special education organizations, interest groups, and associations are also in the process of publishing analyses and commentary. The following list of articles includes overviews of the new legislation and some analyses of specific provisions, as well as additional information about what Section 504 of the Americans with Disabilities Act means for children with disabilities.

CEC Sends Recommendations For IDEA Regulations To OSERS

Ballard, B. Joseph. CEC, The Council for Exceptional Children. The Council for Exceptional Children, July 28, 1997. (See Internet address on page13)

The Office of Special Education and Rehabilitative Services (OSERS), Education Department, invited comments from federal, state, and local officials as well as educators and parents on the IDEA (Individuals with Disabilities Education Act) reauthorization. This letter, written by B. Joseph Ballard, Assistant Executive Director of Public Policy at the Council for Exceptional Children (CEC) and published on the Internet, details the CEC's comments on the regulatory phase of the reauthorization.

Congressional Analyst: IDEA Won't Preclude Alternative Placements

The Special Educator, June 20, 1997. Vol. 12 (22), pp. 1, 7.

The new Individuals with Disabilities Education Act (IDEA) bill requires that a state must ensure that "a free appropriate public education is available to all children with disabilities residing in the state between the ages of three and 21, inclusive, including children with disabilities who have been suspended or expelled from school." In a report prepared by the Congressional Research Service, analysts claim that the new IDEA will not limit schools' ability to provide alternative placements for children who are suspended long term or expelled, or prevent schools from ceasing educational services for students suspended for 120 days or less. These issues and concerns about IEP language in the new IDEA are discussed.

Discipline Ruling Immediately Impotent Following IDEA Approval

The Special Educator, June 20, 1997. Vol. 12 (22), pp. 6–7.

In this article, the author discusses reauthorization of the IDEA as it relates to the ability of a school district to expel or suspend a disabled student for more than 10 days and cease educational services if his or her behavior is not a manifestation of the disability. Case law relative to interpretation of the previous IDEA on this subject is chronicled. Unlike its predecessor, the new IDEA clearly calls for continued services for long-term suspended and expelled students with disabilities.

Expert Gives Administrators Early Answers On IDEA

The Special Educator, June 6, 1997. Vol. 12 (21), p. 2.

In this article, Art Cernosia of the Northeast Regional Resource Center, answers questions about provisions of the new IDEA. Topics include the following: manifestation determination as it relates to the IEP; parent membership on planning teams; mediation sessions; FAPE (free appropriate public education) as it relates to charter schools; private school funding; and participation of regular education teachers in residential school settings.

IDEA Amendments of 1997

Kupper, L. (Ed.); Conroy, M.K. (Assoc. Ed.). June 6, 1997 NICHCY News Digest, 26.

This 60 page briefing paper from the National Information Center for Children and Youth with Disabilities is designed to provide readers with an overview of the major changes to IDEA, as well as a

detailed, point-by-point look at the law, including the verbatim language of the law itself. Components of the two laws are displayed side by side on the page in order to afford the reader the ability to compare specific aspects of each law. The document is available free from NICHCY at (800) 695-0285 or from their web site. (See page 13)

IDEA : Questions and Answers

U. S. Department of Education. 1997. (See Internet address on page 13)

This information sheet, published by the U. S. Department of Education on the Internet, provides answers to questions about new provisions of the 1997 Individuals with Disabilities Education Act. Nine questions are presented and answered.

IDEA V. Section 504 Identification : How to Know the Difference

The Special Educator, June 20, 1997. Vol. 12 (22), pp. 10–11.

In this article, eligibility criteria as they relate to the IDEA and Section 504 of the Americans with Disabilities Act (ADA) are discussed. A breakdown on Section 504's definition of a qualified individual with a disability as a means to determine his or her eligibility is included. Terminology in the two laws are contrasted: Section 504 guarantees FAPE (free appropriate public education) for anyone whose physical or mental impairment "substantially limits" one or more major activity, while IDEA provides FAPE to students meeting one or more of 13 specific categories of disabilities that "adversely affect a child's educational performance."

The New IDEA And Placement Changes:

Taken from Section 615: Procedural Safeguards

The Special Educator, June 6, 1997. vol. 12 (21), p.2.

In this article, language of the previous Individuals with Disabilities Education Act (IDEA) and the reauthorized version are compared as they relate to five placement issues in the education of students who are disabled. These issues are as follows: maintenance of current educational placement, placement in alternative educational setting, and authority of school personnel; determination of alternative setting; notification of action; authority of hearing officer; and placement during appeals.

1997 Individuals With Disabilities Education Act Analysis

Cahir, William J. Special Education Report, July 9, 1997. Virginia: Capitol Publications, Inc.

The new IDEA is discussed. While it preserves the guarantee of a free, appropriate public education (FAPE) to students with disabilities, it imposes new obligations on states and schools, establishes an array of new discipline procedures, and links some new funding provisions to major increases in federal spending. It also adds a series of requirements for individualized education programs (IEPs).

Section 504 : The "Other" Law

The Special Educator, August 16, 1996. Vol. 12 (2), pp. 1, 6–7.

Section 504 of the Rehabilitation Act of 1973 is an anti-discrimination statute that protects children eligible for IDEA services. The article discusses regulations requiring districts with more than 15 employees to appoint a Section 504 coordinator and to adopt grievance procedures to resolve complaints. A sample Section 504 grievance procedure is included. Provision for Office for Civil Rights (OCR) formal complaint is mentioned.

The Special Educator 1997 Desk Book

Pitasky, Vicki M. Horsham, PA: LRP Publications, 1997. (See Internet address on page 13)

This book reviews legal interpretations and court actions concerning special education law (Section 504, IDEA, and the ADA) from 1995-1996. Programs and services under IDEA explored: attorney's fees, discipline, free appropriate public education (FAPE), funding, individual education programs (IEPs), Part H, placement, procedural safeguards, and remedies. Under Section 504 and the ADA, subjects explored include: accommodations, attorneys' fees, discipline, discrimination, extracurricular activities, and remedies. Related laws and federal programs, i.e., Medicaid and Social Security, and miscellaneous legal actions involving students with disabilities and personnel are also included. Appendices provide a table of cases, review of significant cases and reprint of sections of IDEA, Section 504, Assistance to States for Education of Children with Disabilities, and Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving or Benefiting from Federal Financial Assistance. Cop-

ies may be ordered from LRP Publications, 747 Dresher Rd., P.O. Box 980, Horsham, PA 19044-0980, (215) 784-0860.

Internet Resources

The Internet is a valuable source of information for full text versions of the new amendments or for current postings of interpretations and commentary. Consider the following sites:

http://www.ed.gov/offices/OSERS/IDEA/

This is the U.S. Department of Education, Office of Special Education and Rehabilitative Services. Has full text, summary, an overview and questions and answers about the new law.

http://www.nichcy.org/

NICHCY is the national information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals.

http://www.lrp.com/ed/

LRP's Education Administration Online is largely a fee based service for many special education resources, but it does have a number of valuable free resources related to IDEA.

http://www.fcsn.org/home.htm

Federation for Children with Special Needs has text of bill and outline of major changes.

http://www.cec.sped.org/home.htm

Council for Exceptional Children, Public Policy and Legislative Information section is a good resource for updates on IDEA and commentary regarding policy formation.

http://www.access.digex.net/~edlawinc/

EDLAW, Inc., provides a starting point for basic legal information of use to special educators and families and includes public information including, texts of statutes and regulations as well as attorneys who represent families of children with disabilities.

Katlyn's Hope

A Not-for-Profit Corporation Established to Assist in the Education of Deaf-Blind Children

Shari Willis

Katlyn's Hope, Inc. is a not-for-profit corporation established to provide scholarships to assist in the education of children who are deaf-blind . It was founded in memory of our daughter Katlyn Michelle Willis who was born on June 29, 1995 and died on February 7, 1996. Katlyn was born prematurely and had microphthalmia and a moderate hearing loss. We always knew she was a bright little girl who just needed a little help to see the world in which she lived.

Though we knew of Katlyn's disabilities from the time she was born, we had the same expectations for her as we would for any other child. We knew her capabilities were limitless and tried to expose her to everything other children were exposed to. Though her vision and hearing were impaired, we knew she could experience the world through touch. Katlyn was as capable of learning as was any other child, so long as information was provided to her in a manner she could use.

When Katlyn was 5 months old she contracted the respiratory virus, RSV. As a preemie, she had a weak immune system that was very ineffective at fighting off the virus. After a month in the hospital she seemed to have recovered from the illness, but at the end of January, while still in the hospital, Katlyn contracted another respiratory virus. She fought very hard and was very brave. On February 6, Katlyn returned home. On February 7, 1996, she left this world, leaving behind many wonderful memories of a life with a very special little girl.

During her brief life, Katlyn had a profound impact on our lives. Among other things, she taught us a lot about deaf-blindness. We found very hard to find adequate educational services for our baby, quickly learning how difficult it is for parents to find and fund appropriate services for their deaf-blind children. In Katlyn's memory, we want to help other children gain access to the world around them as Katlyn did.

The scholarships given in Katlyn's memory are to be used for interpreter/intervenor consultation, in-home training, educational toys and materials, assistive devices such as hearing aids, glasses, conformers, and canes, and other educational necessities. Stipends are also to be given to families to help them travel to conferences and workshops and to provide interpreters/intervenors for deaf-

blind children at the meetings. All children who are deaf-blind and between the ages of birth and 21 are encouraged to apply.

To date, Katlyn's Hope has presented six scholarships. Two were awarded on June 29, 1996 (which would have been Katlyn's first birthday). Miles Williams of Minneapolis, Minnesota received the Katlyn Willis Memorial Scholarship. The Raymore Lions Club Deaf-Blind Scholarship was presented to Colleen Salka of Monroe, New York. Two more scholarships were given on October 26, 1996. The Dallas Howard Memorial Scholarships were presented to Austin Clifton of Rose Hill, Kansas, and Emily Baxter of Moundridge, Kansas. The most recent scholarships were awarded on June 29, 1997. Jessica Humphrey of Hutchinson, Kansas received the Katlyn Willis Memorial Scholarship. The Wichita Spas Plus scholarship was awarded to Leanne Reed of Ozawkie, Kansas. Kaytlin's Hope is funded by a variety of fundraising activities and by donations from businesses, families, and individuals.

To receive applications for both scholarships and family travel stipends or for further information, please contact

Shari Willis
303 South Elm St.
Wellington, KS 67152
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You are welcome to copy articles from *Deaf-Blind Perspectives.*

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From the Managing Editor

With this issue of Deaf-Blind Perspectives I assume the role of managing editor and would like to introduce myself. I have been at Teaching Research since last February. I am an Information Specialist at DB-LINK and also work part-time for NTAC helping with publications-related issues. I am originally from the Pacific Northwest, but lived in Vermont for several years before moving to Oregon last winter. In the past, I was a registered nurse, working primarily in pediatrics and neonatal intensive care. I then obtained a Master's Degree in Librarianship in 1992 and worked as a medical librarian and writer before coming to Teaching Research.

I would like to take this opportunity to encourage you to write Letters to the Editor regarding articles published in Deaf-Blind Perspectives or on any topic or issue related to deaf-blindness that is important to you. I would also like to invite you to submit manuscripts for possible publication. Manuscripts may be either personal in nature, such as an essay, or professional articles with a specific focus. All submitted manuscripts go through a review process to consider whether they will be published in Deaf-Blind Perspectives.

I am very much looking forward to my work with Deaf-Blind Perspectives. Feel free to contact me if you have any questions, comments or suggestions.

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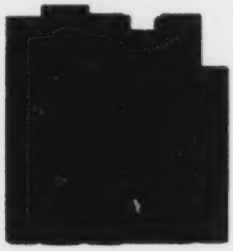

For Your Library

Early Interactions With Children Who Are Deaf-Blind

Gleason, Deborah. DB-LINK, May 1997 Fact Sheet. Length: 8 pages.

Details early intervention routines for infants and young children. Available from DB-LINK: (800) 438-9376.

CHARGE Summer Institute 1996 Proceedings

Published as a cooperative effort between the New York and New Jersey State Technical Assistance Projects and DB-LINK. Length 22 pages.

Proceedings of the 1996 Summer Institute on CHARGE Association held August 4-5, 1996 in Woodcliff Lake, New Jersey. Includes the following papers: "Growing Up with CHARGE" by Kim D. Blake; "My Perspective as An Audiologist" by James W. Thelin; "Swallowing Disorders" by Justine Joan Sheppard; and "How to Make Pre-School/School Work for Your Child: Considerations and Approaches to Maximizing Your Child's Communication and Mobility" by Caren Mercer and Stuart Filan. Available from DB-LINK: (800) 438-9376.

Usher Syndrome in the School Setting

Miner, Ilene; Cioffi, Joe / Helen Keller National Center, Technical Assistance Center 1997. Length 47 pages.

Intended for high school students, teachers, support staff, vocational rehabilitation counselors, and family members. Topics include: defining Usher syndrome, common experiences of people with Usher syndrome, Usher syndrome and the family, orientation and mobility, and vision assessment. It can be purchased through HKNC for $3.00. For more information, contact Kathy Michaels, (516) 944-8900, ext. 307.

DB-LINK Databases on the World Wide Web

DB-LINK (The National Information Clearinghouse On Children Who Are Deaf-Blind) is pleased to announce that the Catalog and Resource databases can now be accessed via the World Wide Web at **http://www/tr/wou.edu/dblink**

As always, DB-LINK may be contacted through their toll-free 800 numbers, e-mail, and U.S. Mail.

DB-LINK
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Monmouth, OR 97361

800.438.9376 Voice
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DB-LINK Survey

This issue of *Deaf-Blind Perspectives* contains a survey from DB-LINK. The purpose of this survey is to sample the readership's interest in and access to information. Your answers and suggestions will assist DB-LINK staff in planning their direction for future information dissemination. Upon completion, simply fold the survey with the return address showing, staple and drop in the mail.

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Deaf-Blind Perspectives

Volume 5, Issue 2 Winter 1997-98

History and Change in the Education of Children Who Are Deaf-Blind Since the Rubella Epidemic of the 1960s: Influence of Methods Developed in the Netherlands

Dr. J. van Dijk
Instituut voor Doven
in collaboration with
Catherine Nelson
University of Utah

The approach to education of individuals who are deaf-blind has changed significantly since the rubella epidemic occurred in the United States and Western Europe in the early 1960s. Prior to the epidemic, only incidental successes in educating children who are deaf-blind had been reported. In the United States, Samuel Gridley Howe wrote in a detailed manner about his student, Laura Bridgman, and Anne Sullivan reported on the enormous educational progress of Helen Keller. In Norway, Ragnild Kaata, a deaf-blind student, was taught to talk, and in France, Marie Heurtin received wide attention for the level of language she was able to attain. This article examines how methods developed in the Netherlands influenced later theories and practices in the education of these children and how those theories have evolved and changed over time.

Early educational methods were well documented and certainly inspired professionals who saw themselves confronted with the multitude of problems presented by children rendered deaf-blind by rubella. Since educators in the United States, at Perkins School for the Blind, had the longest history of deaf-blind education and already had established teacher training courses prior to the rubella outbreak, professionals in Europe turned to them for support. Young European educators of the deaf-blind were enrolled in teacher training programs in the United States and, together with the staff of the American Foundation for Overseas Blind (AFOB), used their newly acquired knowledge to establish eight training courses held from 1968 to 1975 in Sint-Michielsgestel (the Netherlands) and at the AFOB headquarters in Paris. Virtually all Western European countries participated in these six-to eight-week courses. The format of the courses was rather unique. As their colleagues observed, teachers of Sint-Michielsgestel demonstrated teaching techniques they had developed. After each session, a general discussion took place. Because of this early United States -Western European cooperation, the ideas of deaf-blind education that grew out of the AFOB courses at Sint-Michielsgestel found their way to newly founded programs in Scandinavia, Belgium, and Holland and to a lesser extent, Germany, France, and the UK.

In This Issue

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What Were the New Ideas?

Traditional deaf-blind programs were mainly geared to children who were thought to have what was considered good educational potential. The curriculum emphasized classroom activities (e.g., development of sensory motor skills such as sorting objects and matching) and above all, the development of communication. This type of program was not appropriate for the "new" population of deaf-blind. Particularly in the rubella population, traditional classroom activities were overpowered by the motor clumsiness of this population. Training of motor skills was a prerequisite to the development of any form of formal communication, be it fingerspelling, speech or signing. As research substantiated these observations, a

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program was developed with motor development as the central component. This approach was in line with the emphasis remedial education of that time placed on the development of gross and fine motor skills (Kephart, 1960; Bannatyne & Bannatyne, 1973; Bladergroen, 1971).

During the 1965 Kalundborg conference (Denmark), a film called "Motor Development in the Deafblind Education" was shown in which Jan van Dijk from Sint-Michielsgestel showed the beginning steps of deaf-blind education. Two parts of the film attracted wide attention. The young rubella population exhibited considerable delay in both their motor functioning and social skills. The majority of children in this group were withdrawn into their own body activities and therefore paid little attention to other people in their world including the teachers or parents who tried to come in contact with them. This was true both, of the children who were completely or almost blind and those with residual vision. There was, however, one way to successfully attract the children's attention: joining in their favorite activities (e.g., moving hands in front of their eyes, rocking, jumping or spinning around). This "moving-acting together" as Van Dijk called it, was in sharp contrast to approaches practiced with persons with cognitive disabilities in which these activities were stopped by taking their hands away from their eyes or even strapping them down. The co-active movement approach advocated by Van Dijk caught on because of its approach of "joining in" with the child and following his or her attention and interest. It was truly a child-centered approach that included imitation of the child and giving him or her the lead, so he or she would not become totally dependent on the teacher's activities. In the coming theories of child development, this approach was to be called "feeling of competence" meaning fostering the feeling in the child that he or she can have an influence on the environment instead of being completely dependent upon it. In co-active activities, the educator literally feels what the child's intentions are. When moving and acting together the educator is able to perceive the topographically subtle intentive movements the child sends out and may act accordingly.

Attachment Theory

Modern insights into child development have shown how well chosen the ideas of co-active movement were. Currently, a well-researched theory, the Attachment Theory, is gaining wide recognition. It appears that if a child's intentions, which may be subtly expressed through eyes, physical movements, and changes in breathing, are picked up on by the principal caregiver and responded to accordingly, the child will begin to feel that this is a safe person who can be trusted in times of need. In other words, a bond is established between child and caregiver which will serve as a "safe harbor" for the rest of the child's life.

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Conversations

This idea of following the child's lead and responding to his or her intentions has only gained in prominence over the years. The same can be said about another theme of the 1965 film made at Sint-Michielgestel. A scene is portrayed in which one of the finest teachers of the deaf-blind, Mary Jurgens, communicates with a nonspeaking, nonsigning, deaf-blind boy. Co-actively, they are making a doll out of clay. Together they roll a kind of sausage representing the leg of the doll. Then Mary guides the child's index finger to point to the "sausage", then to her legs and to his legs, and finally to the missing part of the clay doll. He understands it, and with her help completes the clay doll including its leg. A conversation has taken place through pointing and referring to the situation (missing leg). The teacher has made herself understood by guiding the situation in such a way that the boy had to understand her intent. He added his part in the conversation by putting the leg in the right place. This is exactly what Van Uden, meant by having a conversation with a speechless (and nonsigning) deaf-blind child (1967). His conversational method has always been influential, not only for deaf, but also for children with deaf-blindness. Important features in this method such as turn-taking, mutual gaze or the looking to things together (e.g., child and educator or child and parent), and the use of pointing (deixis) have been found to be essential elements in the development of language, as was demonstrated in research that came out many years later (Ninio & Snow, 1996; Preisler, 1983; Volterra & Erting, 1990).

It goes without saying that such conversations must have a subject. Children who are deaf or nonverbal with hearing can be very clear about what it is they want to communicate about. They may look towards things, move towards something, or bring an object to a person. Most children who are deaf-blind do not show their intentions so clearly. Therefore in the early Van Dijk theory, the topic of conversation was elicited by making the experience very concrete. If the child participated in an activity he or she enjoyed such as swimming, an object associated with this activity was presented. Through pointing to the object, gesturing, and in some instances talking to the child, the experience was discussed: "you" (pointing); "me" (pointing with the child's finger and teacher's body); "swimming" (pointing to the water wings); "you" (pointing); "splash, splash" (co-actively splashing). A model of the swimming pool might be present with chlorinated water in order to depict the situation as vividly as possible. These objects called "objects of reference" were, and are, intended to serve as a concrete aid for engaging in conversation with the child.

Objects of Reference

In his early work with deaf-blind children, Van Dijk and his coworkers stuck the objects of reference to wooden boards and sorted them according to conversation topics. Later the objects were also used to announce the activity (e.g., presenting the entire water wings or a portion to indicate actually going to the swimming pool). The use of the objects of reference for this function is now widely used with people who have all types of significant difficulties in communication. A group of special educators in the U.S. have expanded considerably upon the idea of the objects of reference. On a video tape, Rowland and Schweigert (1996) demonstrated step-by-step how the objects can be used.

Calendars

From the same basic question of how to come into conversation with the child, grew the idea of calendars. By ordering the days/weeks/months according to their main activity and putting the objects of reference in the time order of the day/week/month, conversation can be enhanced. When the objects of a specific event are arranged in a box, they can serve as a support for the child's memory of episodes in his or her life. In a true conversation, both partners play an active role. By the nature of his sensory impairments, a child who is deaf-blind must be introduced into a situation which enhances expression, either through touching the objects, pointing to them, or having them arranged in a way that represents what the child has experienced. This gives the child the chance to be an active participant, rather than a person who is simply handed objects and is then compelled to proceed to the activity the objects refer to.

Play

Our Russian colleagues have made us aware of how objects of reference can be included into the development of play in children who are deaf-blind. Since the political barriers were eliminated, western deaf-blind experts have become aware of how much Russian deaf-blind education has to offer. The educational practices described here could be enriched by including play activities in a methodical manner. In the Russian method of deaf-blind education, one starts by depicting the child's experience through the use of dolls. The child is asked to make compositions that resemble real life. Gradually, the teacher adds her part and together they move gradually away from the concrete reality into the world of fantasy in which accompanying language plays an in-

creasingly important role. It is very important to note that Russian deaf-blind education has a strong social component. Its purpose is to have a group of students participate in the activities, asking one another about the experience his or her playmate has gone through. Eventually, the conversation is put into words, picture books (embossed), or in large print and these products are put on display in a central location, preferably a library so that other students can read the stories of their peers.

Social Relationships

Deaf-blind education in the Netherlands has always had a strong emphasis on the development of social relationships. Conversation, the major principle of working with deaf-blind children, was stressed from the beginning. Social relationships are an integral part of conversations between communication partners. However, in some instances, despite intervention by the teacher or caregiver, the child might be unable to play his or her conversational role. In order to prevent the fragile relationship from going astray, the educator might be forced to prompt the child with an object indicating that he or she wants the child to participate in an activity. This may lead to a one-sided, teacher-oriented approach that may be socially undesirable, but necessary. Sometimes this situation arises because the educator lacks the skill to engage the child in meaningful communication and then overlooks the child's communicative intents for the sake of her own dominance. The theory itself, however, is not responsible for such poor implementation.

Over the years, we have become very aware that it takes good on-the-job supervision and carefully planned training to develop true conversational skills in educators. Present research should be continued to develop teacher training and corresponding parent programs to address this need.

Questions Remain

While parts of our original theories have evolved over time, it can be stated that a number of principles of deaf-blind education developed in Europe still hold and are even stronger as many have received support from developments in the scientific field of early childhood and early language development. Far from anecdotal are the comments of teachers of the deaf-blind all over the world who have put our ideas into practice: "It really worked!" There are, however, a few points that continue to need evaluation:

- The role of sign language in deaf-blind education
- The role of the parents in the decision-making process
- The role of inclusion.

The Role of Sign Language

In early educational programming, the development of "private signs" created by a child was encouraged. This might be a simple hand movement to indicate a wish to switch on the fan or a finger movement to express the desire to continue playing the drums. It was stated as early as 1967 by Van Dijk that the private signs that the child developed himself could be expanded to signed Dutch (Van Beek system). He supported the idea of replacing the signs with fingerspelling or even speech using the Tadoma method. Fingerspelling was encouraged because at that time it was felt to be superior to signing. These views have changed dramatically. It is understood now that sign language is a true, and very effective, language for deaf persons and probably for individuals who are deaf-blind. It was decided fairly recently that the use of sign language for deaf-blind children should be considered as a real option. When the child has sufficient vision, signing can be presented visually, and in cases of blindness or decreased visual capacity (e.g., in persons with Usher Syndrome), tactual signing should be offered at a fairly early age since the earlier this language is used, the better the person's command of sign language will be.

The Role of Parents

In discussions of which language code to use or whether or not to send children to residential settings, the role of parents in some European countries has lagged behind British, Scandinavian or United States counterparts. In these countries, parents have shared in IEP (Individual Education Program) meetings and have had a decisive voice in educational programming for quite some time. In the United States, parents and their young children who are deaf-blind begin receiving assistance and early intervention as soon as the disability is identified. When the children are old enough for preschool, parents have already gained a great deal of knowledge about the needs of their children and have much to offer as educational decisions are made. Although times are rapidly changing in Europe, too little attention has been given to parents who do not want to send their children away and

prefer to educate them with necessary help at home and in their neighborhood school.

The Role of Inclusion

Increasingly, parents want their children educated in the regular classroom with nondisabled peers. The idea of including children with the most severe disabilities in regular education classes is a topic of hot debate in the United States. Is it really effective? Can we really require that a regular education teacher develop the skills to successfully interact with, and teach, children with all different types of disabilities? It is too simple to reject the inclusion movement as a nonrealistic dream. There is ample research showing that simply through observation of their nondisabled peers, children with disabilities can learn social, play, and communication skills. In the coming period, this issue should be looked upon seriously and not rejected out of hand. Types of supports needed by children who are deaf-blind to ensure that learning is enhanced in regular classrooms must continue to be researched as to their efficacy and when and how they should be used. Such supports might include the intervenor system as was developed in Canada and technological advances such as augmentative communication devices and devices for individuals with low vision.

In the early days of deaf-blind education in Europe, as well as in the United States, strong emphasis was placed upon the distinction between educable and trainable children. In the Individuals with Disabilities Education Act (IDEA) in the United States, this distinction is no longer mentioned. All children regardless of their mental and/or physical impairments including combined sensory loss must receive adequate services. The system of consultation is widespread in the United States and a deaf-blind consultant assesses the child and contributes to the IEP and subsequent intervention plans regardless of the level of the child's functioning.

In some European countries, deaf-blind children in institutions for the mentally handicapped receive very inadequate services. Fortunately, it can be said that this is changing rapidly. However, some countries have been slow to admit that the quality of life of children with severe mental disabilities in combination with sensory impairments can be improved significantly with proper intervention. If outcomes for children with such impairments are to improve, government agencies and educational decision makers must be made aware of the right of all persons to the highest possible quality of life and what must be provided in order for them to achieve such a life.

Summary

Through the collaboration and sharing of knowledge of many countries, successful methodologies to teach individuals who are deaf-blind have increased rapidly since the time of the Rubella outbreak. This knowledge has successfully been disseminated to many educators around the world. Such collaboration must stay alive as we address new challenges with a low-incidence and ever-changing population who have demonstrated over and over to us that they can learn when given proper intervention.

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Ways to Incorporate Physical Fitness Into the Lives of Individuals Who are Deaf-Blind

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Physical activity is an essential component of a healthy lifestyle. The following anecdote illustrates some of the difficulties that may occur in individuals who have not had an opportunity to develop physical fitness through regular exercise or activity:

> Juan, a 17-year-old boy who became deaf and blind from Usher Syndrome, has been placed through vocational training as a horticulture assistant for a mall. His commute to work consists of walking a half mile to the bus stop, a 30-minute bus ride and a five-block walk to the mall. His responsibilities at work include planting, weeding, watering, and repotting. Whereas most 17-year-olds could handle this easily, Juan is often too fatigued to complete his work. Physical fitness is limiting him, not only at work, but in all aspects of his life. He could benefit socially and physically by increasing his current physical activity level.

Justification for Physical Activity

Physical activity is defined as any bodily movement produced by skeletal muscle, resulting in substantial increase over resting energy expenditure (Bouchard & Shephard, 1994). Increased physical activity can decrease the chances of dying from heart disease, plus the risk of developing diabetes, high blood pressure, dangerous cholesterol levels, and high stress levels (Surgeon General, 1996). Furthermore, the social and psychological benefits of increased physical activity are tremendous. According to Blessing, McCrimmon, Stovall, and Williford (1993), a regular program of aerobic exercise can improve cardiovascular function and body composition. Many individuals involved in daily exercise report better ability to sleep, improved self-esteem, increased stamina, and decreased stress levels leading to a better attitude about life. Many practitioners also find that when their students are involved in daily physical activity, negative behaviors, as well as self-injurious or self-destructive behaviors, decrease.

Research indicates that children who are blind tend to have more body fat, and less cardiovascular endurance, muscular strength, and muscular endurance than their sighted peers (Lieberman & Carron, 1998; Winnick & Short, 1985). Winnick (1985) has also determined that children who are blind are behind in activities such as throwing, catching, balancing, striking, and body and spatial awareness. Researchers attribute these various delays not to genetic limitations of performance, but rather to overprotection and discouraging attitudes on the part of the parents or teachers (Nixon, 1988; Winnick, 1985). To date, research on the fitness and motor ability of individuals who are deaf-blind is limited, yet one can logically conclude that children who are deaf-blind, due to their additional communication and mobility needs, will exhibit the same or more severe characteristics.

It is imperative to encourage individuals who are deaf-blind to participate in physical activity in school and in their recreational time. The physical, social, and psychological benefits of physical activity will increase the likelihood of independence and improve the quality of life for these children.

Fitness Activities

A complete medical examination is recommended prior to beginning a fitness program. Clearance should be granted by an ophthalmologist for activities involving physical exertion if there is a history of detached retina, retinal bleeding, and other tenuous eye conditions. Once medical clearance is obtained, a fitness assessment should be conducted by a certified person such as a health/fitness instructor, exercise specialist, health or physical education teacher, fitness director, exercise test technologist, or personal trainer to determine a starting reference point. Once the preliminary examinations and assessments are completed, an exercise program should be created to include a warm-up phase, an exercise phase, and a cool-down phase. The warm-up and cool-down phases should have a duration of approximately 10 to 15 minutes and should consist of low-intensity cardiovascular exercise (walking, cycling, aerobics, stretching, etc.). It is essential that the individual choose an exercise activity that he or she enjoys.

Many individuals may not at first like the feeling of discomfort that comes with extended periods of physical activity such as bicycling or running; therefore, short distances and times are recommended. It

is important to set challenging, yet attainable, goals with each person.

For more information on basic fitness principles for individuals with sensory impairments see Lieberman (1996) in the Winter issue of Deaf-Blind Perspectives. The following are successfully tested strategies to adapt fitness activities for individuals who are deaf-blind. Remember that activities should be chosen based on the individual's strengths and weaknesses. In addition, these activities need be adapted to each person to increase the chances of reaching his or her potential.

Bicycling

- Independently: Individuals who have some usable vision may be able to ride a bicycle independently in a quiet park or around a track. Going with sighted companions will help ensure safety.
- Tandem bicycles: Tandem bikes allow the sighted participant to peddle in the front of the bike while the participant who is deaf-blind peddles in the back. The person in front is responsible for steering and stopping. Tandem bikes can be purchased through most bicycle stores and range from $400 to $2,000. To find riding partners, contact your local bicycling club, university, or deaf club. Develop specific signals for turning, stopping, or emergencies.
- Surrey or duo bikes: These bikes enable the participants to ride side by side, making conversation easier. The sighted participant is responsible for steering and stopping. A local bike store can usually supply a catalogue for these bikes.
- Stationary bicycles: Anyone who has some functional use of the legs can use one of these. Many stationary bikes will log the distance traveled and amount of time ridden. They can be purchased for $100 to $1,000 in most sporting goods stores.
- Bicycle stand: Bicycle stands can turn an ordinary 10-speed into a stationary bike. These work like stationary bicycles and can be purchased for under $100 from any sporting goods stores.

Jogging

- Sighted guide: The runner grasps the guide's elbow, shoulder, or hand depending upon what is most comfortable for the runner and guide.
- Tether: The runner and guide grasp a tether which is a short string, towel, or shoelace. This allows the runner full range of motion of the arms, while remaining in close proximity to the sighted runner.
- Sound source: The guide rings bells or shakes a noisemaker for the runner to hear while they run side-by-side. This works best in areas with limited background noise and for runners with enough residual hearing.
- Guidewire: This allows the runner to run independently. A guidewire, set up permanently or temporarily, is a rope or wire pulled tightly across a gymnasium or track. The runner holds onto a sliding device such as a rope loop, metal ring, or metal handle, which prevents rope burn and allows for optimal performance.
- Sound source from a distance: The runner runs to a sound source such as a clap or a bell. This can be done as a one-time sprint or continued for a distance run.
- Sighted guide shirt: The runner with partial vision runs behind a guide with an easily recognizable shirt. This must be done in relatively uncrowded areas.
- Independently around a track: Runners with low vision can follow white lines on a dark track when the track is relatively empty.
- Treadmill: Running on a treadmill provides a controlled and safe environment. Treadmills, which can be purchased at most sporting good stores, cost anywhere from $200 to $1,000. The best treadmill will include a safety feature for quick stops. Many come with timers or mileage readers.
- Wheelchair racing: An individual in a chair can use any of the above adaptations if necessary and appropriate around a track, through the neighborhood, or on a paved path with assistance.

Circuit Training

The safest way to train for muscular strength and endurance is with a circuit of stationary machines. The machines may consist of bench press or leg flexion-extension machines, a sit-up board, or a universal machine. The following strategies will help ensure success:

- Enough time: Allow time for tactile and/or visual exploration when introducing an individual to a machine.
- Demonstration: The instructor should demonstrate the movement and link the movement to language, including the name of the exercise and muscle involved.
- Option to perform: The individual is encouraged to try everything, yet it is important that they understand that they can decline.

The following adaptations may be made:

- Pictorials/braille instructions: Allow time for the person to look at performance pictorials and/or the opportunity to read about it.
- Visual or tactual perimeter: For safety, mark the perimeter of the exercise machines with rope or contrasting colored tape on the floor.
- Adaptations to equipment: Use large print, Hi-Mark and braille to mark on/off switches. Vibrating timers can be worn around the neck or in the pocket.
- Number stations: Use large print, Hi-Mark, and braille to mark each piece of equipment with a designated number. A rope, tape, or tactile guide can lead from one piece of equipment to the next one.

Aerobics

The term aerobics means literally "with oxygen" or the "steady state transport of oxygen to the working muscles" (Shephard, 1990, p. 5). Thus, aerobics involves sustained physical activity to a point at which the body is utilizing oxygen or reaching 60%-80% of maximum heart rate over a period of time. To determine an individual's working heart rate, subtract his or her age from 220, then multiply that number by .60, .70, or .80 depending upon how hard he or she wants to work (American College of Sports Medicine, 1991). For example, Nancy, who is 32 wants to work at 60% of her maximum heart rate. She would calculate 220 - 32 = 188 x .60 = 112.8. This means that Nancy's working heart rate would be 110-120 beats per minute. To see if Nancy is working up to this level, she would sustain an activity such as aerobic dancing, cycling, or jogging in place for 5-10 minutes. While continuing this activity, she would take her pulse for 6 seconds, then add a 0 to her pulse score and compare that to 120. If her 6-second pulse was 14, that translates to 140 heartbeats per minute and she should slow down a little. A pulse count of 10 translates to 100 beats per minute and she needs to step up the pace a little to maintain her desired heart rate. The working heart rate should be sustained for over 15 minutes, and preferably 30 minutes. It's important to start out slowly. Some examples of aerobic activities include the following:

- Step aerobics: This is sustained stepping on and off a 4-, 6-, or 8-inch platform at varying tempos and in different directions. This type of activity is adaptable to any level of ability. If an individual cannot step onto a platform, he or she can do the same activities without it.
- Low-impact aerobics: This is sustained activity keeping one foot on the ground at all times. This includes marching with high knees, kicks to the front, bringing knee up and clapping under leg, marching in place and bringing arms up and down, toe touches to the front, right, and left, or just walking briskly around the room. As long as the individual is moving and keeping his or her heart rate up, this activity can be executed successfully by anyone who is ambulatory.
- High impact aerobics: This is sustained activity with both feet leaving the floor at some point during the movement. This includes jumping jacks, kicks to the front, jogging in place, bringing knee up and clapping under leg with a jump with the other leg, pendulum leg swings out to the sides, side jumps and front jumps in alternating directions. Doing these for any length of time requires good physical condition.
- Wheelchair aerobics: While sitting in a wheelchair, the individual moves his or her arms up in the air, out to the sides, punches down, or twists at the hips for eight counts or more to elevate the heart rate. If possible, the individual can move his or her legs at the same time.
- Physical assistance and/or brailling (Lieberman & Cowart, 1996): When the individual does not have enough vision and/or hearing to understand the details of a movement, the instructor can simplify all the moves to one touch cue or a sign cue that the participant will understand. For example, if the instructor wants the participant to march in place, the instructor would make the sign for soldier or tap the individual's knee to signal marching. Since this has been previously explained, the participant will know what to do until a new cue is given. Routines that are consistent in their content will allow the instructor to gradually fade out cues and will lead to more independence.

- Others: Any activity that raises the heart rate for a sustained period of time is considered an aerobic activity. Cycling, running, swimming, or walking can also accomplish this.

All these activities can be enjoyed with or without music. It is much easier to practice them without music first, then add that variable later.

Aquatics

Swimming is one of the best activities for individuals who are deaf-blind. There are few barriers, and the swimmer can move freely without worrying too much about obstacles. Water can aid in range of motion, balance, stability, locomotion, and socialization. Adaptations for aquatics include the following:

- Flotation devices: A variety of flotation devices is available, and an individual can still receive an aerobic workout while using a flotation device. Kickboards are especially helpful since the board hits the side of the pool before your head does!
- Trailing: Use the wall and lane lines as guides for lap swimming the length of the pool.
- Counter devices: Use flip cards, counters, or rings to assist in understanding of distance traveled or number of laps.
- Hand-over-hand teaching and brailling: for beginners (Lieberman & Cowart, 1996).
- Tread water: As an alternative to swimming laps, treading water provides a good aerobic workout.

Dance

Dancing gives an opportunity for free movement and exercise as well as a chance to be involved in a crowd, bumping bodies, moving, holding hands, and socializing (Smith, 1994). Pay attention to the following:

- Decibels: Play music very loud and turn up the bass. Be sure to inform those with hearing aids before you turn the music up so they can adjust the setting if necessary.
- Beats of music: Strobe lights can reflect the beat of the music or participants can hold a balloon which will pick up the vibrations from the music (Smith, 1994).
- Wooden floor: Dancing on a wooden floor produces vibrations and tactile cues.
- Peer tutors: Peer tutors can model and give physical assistance (Houston-Wilson, Lieberman, Horton, & Kasser, 1997; Lieberman & Cowart, 1996).

Deaf peer tutors are also excellent role models!

Summary

The benefits of physical activity have been well documented, yet many children who are deaf-blind are excluded from participation. Even when included, success or failure depends upon the attitude of the physical educator, teacher, parent, support staff, and the individual him/herself (Downs &Williams, 1994; Rizzo & Kirkendall, 1995). It is hoped that the above suggestions will foster creative ways to adapt attitudes, equipment, and the environment so the person who is deaf-blind may achieve his or her highest possible level of physical fitness. This will in turn lead to greater independence—the key to good job performance and a better quality of life.

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Benjamin's Bar Mitzvah

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With:
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Laurie Roth, Teacher

"My grandpa Ben truly believed that each child had something to teach us, a message that would help explain why we are here. Today, my grandfather would be very proud of me." (Excerpt taken from the dedication of Benjamin's prayer book.)

On March 23, 1996, at the age of 13, Benjamin was called to the Torah. A handsome boy with blond hair, he stood at the *bima* (platform) in a black tuxedo, accompanied by eight friends, his parents, his teacher, the rabbi, and the cantor. Among the 300 people assembled in the sanctuary were Benjamin's relatives, schoolmates, teachers, neighbors, and special guests. After three years of hard work, Benjamin was finally to become a Bar Mitzvah. Bar Mitzvah literally means a boy who fulfills the commandments. It is a rite of passage into adulthood, a celebration that a young man can now participate in the rituals that represent full membership in the Jewish community. On this day, a boy reads the blessings over the Torah for the first time in the Hebrew language.

But Benjamin is a child with multiple disabilities. He has been diagnosed with cerebral palsy, severe mental retardation, hearing loss, and cortical blindness, which refers to difficulty making sense of visual images. Benjamin is not able to speak, but communicates with gestures and vocalizations. He walks with a slow and unsteady gait, often swaying from side to side. He needs constant help and attention for day-to-day routines, like dressing or getting something to eat. Benjamin is usually affectionate and calm, but when he becomes frustrated or upset, he might scream, hit himself, or bite his hands. How, then, could Benjamin be expected to study Hebrew? Recite the prayers? Know the meaning of Jewish rituals?

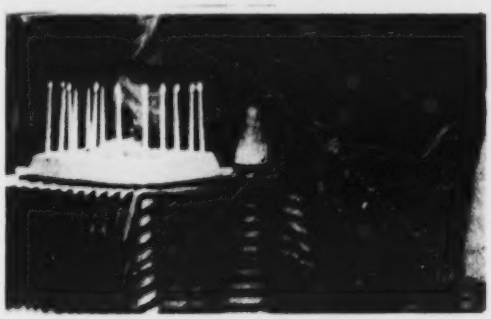
For Benjamin's mother, Carole Devon, a Bar Mitzvah meant more than the ability to prepare for the ceremony: "There is something about a boy having a Bar Mitzvah that transcends going to synagogue. I had thought it meant Hebrew School for three years—read, write, and study. But then I read that if a child could smile at his mother or touch the hand of his father, he was following the commandment honoring his mother and father. He therefore knew a sense of God, and was entitled to a Bar Mitzvah."

The acceptance. Carole, who is Jewish and whose husband David is Christian, set out to speak with the principal of the religious school of one of New York's more liberal synagogues, Stephen Wise Synagogue. The principal suggested that she present her request to the synagogue's Religious School Committee. She explained to the committee how much easier and comfortable it would be, for her as a mother, for Benjamin to stay within a segregated environment because of the nurturing and protection it would offer him. But that wouldn't necessarily be better for Benjamin. She argued that children like Benjamin needed the chance— and the support— to become contributing members of society by being with members of their own communities. About this experience, Carole remarked, "This was the most courageous thing I have done in my life, to put

Benjamin and myself on the line." The committee members voted unanimously to accept Benjamin into the Sunday School.

Now the real worry was to begin. Carole, herself, could not picture how Benjamin might be accommodated. How would the teacher handle this? How could Benjamin participate in lessons? What would happen the first time Benjamin screamed and hit himself? What would the other children think? Carole knew that she would need help. The assistant principal of Benjamin's special education school introduced her to two teachers, Tom and Laurie, who were committed to "inclusion," the belief that individuals with disabilities should be fully integrated with nondisabled people in their schools and communities.

Tom agreed to meet with Benjamin's classmates and their parents a week before Benjamin was to begin. During that meeting, he described Benjamin's physical appearance, his way of communicating, behaviors they might observe, and his interests. He was prepared to address their anxiety about how Benjamin's presence might interfere with the children's study but instead, they talked about Benjamin's abilities more than his disabilities.



Laurie volunteered to attend Sunday School with Benjamin. She would involve him in activities, adapt materials, and attend to his personal needs. What began as a simple act of goodwill turned into a promise to her grandmother that she would see Benjamin through to his Bar Mitzvah. Over the course of three years, her role would evolve from that of Benjamin's personal teacher to that of classroom facilitator.

The first year. To any parent, a child's first day of school is a time of anxiety. For Carole and David, it was no different. What made Carole apprehensive was how the other children would respond to Benjamin. In fact, her initial fears were legitimate. On their first day together, all of the children stared at Benjamin. For no apparent reason Benjamin had a tantrum. He yelled, smashed himself against the desk, and threw himself back toward the floor. Laurie took Benjamin out of the room so he could calm down. When they returned, the children in the class asked, "Is he okay?" "What's wrong?" "Did I do something to upset him?" Laurie explained this was Benjamin's way of communicating that something bothered him, that maybe he was bored, nervous, or hungry. The children were scared and concerned, and they didn't quite know how to respond to him. So they stayed away from him.

Over the next two weeks there was little change. When his classmates did interact with him, they took on a role that was closer to a care provider than a peer, and they typically spoke to Benjamin as if he were a baby. There was also a physical distance between Benjamin and the other children. His classmates did not want to sit near him or touch him. They would be out the door and down the hall before Benjamin even stood up from his desk. When they moved from the classroom to the sanctuary, the children would run up or down the five flights of stairs and leave Benjamin behind to take the elevator alone with the teacher.

Things changed around the fourth week. One boy, Zach, had been observing Benjamin, quietly showing interest from a distance. During a class break, he began to ask Laurie about Benjamin. He asked if Benjamin could read, if he liked music, if he could feed himself, and if he could go to the bathroom by himself. Everyone in the class stopped to listen. Of all of the children, Zach bonded most quickly with Benjamin. He began talking to Benjamin. He sat next to him in class. He seemed comfortable with Benjamin.

Over the next several weeks, there were gradual but noticeable changes in the way the children interacted with Benjamin. As they arrived in school, they would approach Benjamin to say hello. They volunteered to help him walk to the sanctuary where services were held. They got Benjamin to participate in folk dances during music time.

Initially, Laurie and Benjamin sat together in the back of the classroom and did parallel activities while the other children did their work. If the children were studying from their textbooks, Laurie might read aloud to Benjamin or help him do an art activity related to the lesson. By this time, the other children began offering ideas of how to include Benjamin. One boy suggested that he, rather than Laurie, read aloud to Benjamin. One of the girls wanted to make a collage with Benjamin to depict a religious passage from the text.

Not every child, however, would come to accept Benjamin. As the year progressed, one boy became increasingly disturbed by Benjamin's presence. He

would call Benjamin names and offer negative remarks about him to his peers. Before year's end, the boy withdrew from Sunday School. But at the last session before summer vacation, all of the children went up to Benjamin. They told him they would miss him.

A circle of friends. In the fall, Benjamin and his classmates had a new teacher. Zach, Benjamin's closest friend in Sunday School, had left the temple. Yet, the children picked up right where they had left off. They came in on the first day and asked to see Benjamin's pictures from summer vacation. When Benjamin yelled or hit himself, the children explained to the new teacher that Benjamin was tired, maybe bored. Early on, it was evident that Benjamin was accepted and embraced by his peers.

Carole was delighted. "Truthfully, it's worked out beautifully. Last Sunday they wanted to go up on the roof because the weather was nice. The teacher said, 'Well, we have a lot of things to go over.' And Benjamin let out a little, you know—one of his things— and all the kids said, 'See, Benjamin doesn't want to study. He wants to go on the roof.' And that's what they did. They all went to the roof."

By then, Benjamin was learning to use an electronic communication device called the Speakeasy. The Speakeasy can record and store in its memory several different messages. Each message can be played out loud by pressing a different switch or key. When Benjamin first brought the Speakeasy to Sunday School, it was only programmed to say "Yes" and ""No." Carole recalled, "A couple of the children in the Sunday School class came up and said they thought this was very unfair, that Benjamin had things he wanted to say, and that he shouldn't always be required to be answering 'Yes' and 'No' and 'I don't know.' So the twelve children—and there was a big battle between gender because at first they wanted boys' voices for the Speakeasy because he is a boy, but the girls were having none of that—so everyone programmed in what they thought Benjamin wanted to say. We let them make it up as long as it was relevant to Benjamin, such as 'I want to go out and play.' Some of the boys got together laughing. They had to program something his mother was not allowed to hear. One was 'I have to take a whiz,' which I guess is 12-year-old vernacular for 'I have to go to the bathroom.' This was very important to them. Kids actually programmed in what they knew another 12-year-old would want to say."

Interactions between Benjamin and his friends were frequent now that a barrier to communication was removed. The children would sit close to Benjamin to ask him questions and wait for his responses. They would touch him on the shoulder to prompt him to use the Speakeasy, or bring his hand to the switch so that he could make a comment or request. It was as if the Speakeasy provided Benjamin and his peers with a common means of expression.

So, too, did Benjamin's participation in religious studies increase. During the first year, he was literally a figure on the perimeter. When the class performed a Bible story, Benjamin's role was to stand on the side and hold up cards with the written text of the skit. By their third year together, his classmates created parts for Benjamin. For instance, knowing that Benjamin liked to bang things, his classmates brought a chair to the front of the room, gave him a gavel, and made him the judge. Whenever he banged on the desk, one of his classmates yelled, "Order in the court!" Benjamin also participated in religious services and presentations to the congregation. The children would record portions of a certain prayer into his Speakeasy and Benjamin would press a switch to recite the prayer.

An unexpected problem developed the last year which seemed sure to jeopardize Benjamin's Bar Mitzvah, as well as his friendships. The class was switched from Sunday morning to Tuesday evening. Benjamin had a hard time staying awake. He would fall into a deep sleep and have tantrums when he was roused. One time he accidentally hit his teacher when she tried to wake him up. His agitation was beginning to disrupt the students' ability to concentrate on their work. Both Carole and David worried that Benjamin would have to withdraw from the program.

Laurie approached the children and told them she needed their help. She asked the children for their ideas, and eventually, they came up with a solution. Benjamin would practice his Bar Mitzvah routine in the sanctuary with Laurie for a portion of classtime. Benjamin and his classmates would still see each

other every week before and after the lessons. Every two or three weeks Benjamin would return to the class for the entire evening. The children would all perform a skit about the passages they had studied in his absence. His classmates would create a role for Benjamin so that he could participate in the play as well.

The ceremony. "For his Bar Mitzvah," Carole recalls, "Benjamin's classmates all volunteered to participate. And believe me, it has to come from love because no one wants to learn Hebrew to speak in front of 300 people, let alone do it a second time."

As part of the Bar Mitzvah ceremony, Benjamin would have to recite several prayers. Benjamin's classmates decided that they would all help him with his readings. Each classmate would select one of the prayers, and record part of it onto Benjamin's Speakeasy. During the ceremony, each child in turn would accompany Benjamin to the pulpit. The child would assist Benjamin to activate the Speakeasy, and the passage would be played over loudspeakers. The classmate would then chant the remaining segment of the prayer that he or she had previously recorded.

Benjamin with New York Mayor, Rudolph Giuliani

From beginning to end, the planning and rehearsal of Benjamin's Bar Mitzvah took seven months. Benjamin and his classmates, Laurie, the rabbi and the cantor, rehearsed the ceremony step by step. They repeated the songs and blessings until they felt that Benjamin was familiar with them. They programmed the Speakeasy, figured out where to place it on the *bima*, and decided on how to cue Benjamin to press the switch at the right time. They thought about what they would do in case Benjamin got tired or frustrated.

On the day of Benjamin's Bar Mitzvah there was much spirit and joy in the synagogue. Somehow having learned of Benjamin's special ceremony, a local television station dispatched a news team to cover the event, adding to the excitement. The Mayor of New York City also made an appearance to honor the boy whose acts of faith were about to be celebrated.

As the music began, Benjamin was led by his classmates to his place on the *bima*. The rabbi made welcoming remarks, and talked about the symbols of the ceremony. He called on Benjamin's grandmother and two aunts to say the first *aliyah*, or blessing, over the Torah, and Benjamin's three cousins, Sabrina, Sasha, and Samara to recite the second blessing. Benjamin was called to make the third *aliyah*. He arose with the help of his classmate, Jesse, and walked to the pulpit. The blessing was recited perfectly, and one could hear the collective sigh of Benjamin's classmates. Then, one by one, they helped Benjamin chant the blessings, as they had so carefully practiced, with confidence and pride. Benjamin handled it like the young man he had just become. There were no tantrums, yelling, or hitting, as some feared.

After the religious service, a celebration took place in the synagogue's large reception room. Balloons, music, and laughter filled the room. Benjamin's classmates swarmed around him. They held his hand, patted his back, talked with him, and danced with him. Watching the children interact with Benjamin on this day, no one would have known that the initial weeks of his involvement in Sunday School were so tense and difficult. In a special prayer book for the occasion was a letter from Benjamin to his classmates:

You accepted me as a friend and classmate. You always looked at what I could do — not what I could not do. You always let me be who I am. I have never spent time with typical children before this experience. If all children are like you, then children like me really do have a chance at life.

Now, nearly six months since the Bar Mitzvah, Carole had hoped that Benjamin and his friends would maintain contact. But they have seen each other only once or twice since last March. Carole knows she must take up the challenge again so Benjamin can have opportunities to be with peers and maybe make some new friends. She also knows that it will be difficult to find community programs that will readily accept Benjamin. "I want for my child the same thing that everybody wants for their children, which is to help them be the best they can with what they have been given. I don't know if that means keeping them segregated or not keeping them segregated, but I know the more normalized I can make his existence, the better it's going to be for Benjamin later on."

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DB-LINK

IDEA 1997 - Product Updates

In the last issue of *Deaf-Blind Perspectives*, Fall 1997, DB-LINK contributed a list of articles and materials pertinent to the reauthorization of the new Individuals with Disabilities Education Act Amendments of 1997. We are just beginning to see the new wave of materials designed to inform school districts, teachers and parents about the new provisions and legal requirements of this act. Following are two titles recently added to the DB-LINK shelves.

The Individuals with Disabilities Education Act Amendments of 1997: Curriculum, Office of Special Education Programs U.S. Department of Education, 1997, Washington, D.C.

This two volume set is a cooperative publication between Office of Special Education Programs (OSEP), the National Information Center for Children and Youth with Disabilities (NICHCY), and the Federal Resource Center for Special Education (FRC). The curriculum is designed as training materials for parents, administrators, teachers and advocates. The Curriculum includes more than 500 pages of background information, resources, handouts and training scripts on the law. Pertinent sections cover Appropriate Evaluation, IEPs, LRE and Parent & Student Participation. Information is presented employing a variety of strategies consistent throughout the chapters, and includes an accompanying set of 145 overhead transparencies. The cost of the two volume set is $175.00 and is available from NICHCY. Contact NICHCY for more information at (800) 695-0285.

1997 IDEA Amendments: An Overview of Key Changes, LRP Publications, 1997, Horsham, PA.

This recent LRP publication summarizes important changes in the new law. Summaries and assessments of the changes are written by nationally know experts in the field. A good reference for translating the law into language that is accurate and accessible. Available from LRP Publications for $14.85. Contact LRP at (215) 784-0860.

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The Canadian Deafblind and Rubella Association (CDBRA) Announces Conference

The 6th Canadian Conference On Deafblindness

Hosted by The Ontario Chapter of CDBRA

Theme: "Let's Celebrate Our Harmony Together

Dates: August 12-15, 1998

Location: Delta Meadowvale Resort and Conference Centre
Mississauga, Ontario Canada (Part of the Greater Toronto Area)

Save with early registration by May 31, 1998

With harmony as the theme, this conference will focus on the cooperation of consumers, families, professionals, organizations, and governments to ensure that persons who are deafblind achieve the best possible quality of life. Topics that will be specifically addressed in relation to the theme will include: Deafblindness, Intervention, Communication, Education, Medical Issues, and Independence/Advocacy.

For further information please contact:

CDBRA Ontario Chapter
350 Brant Ave
Brantford, Ontario
Canada N3T3J9

Ph: (519) 754-4394
Fax: (519) 754-0397

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The American Association of the Deaf-Blind Announces National Convention

June 13-19, 1998

The American Association of the Deaf-Blind (AADB), originally established in the late 1930s, is a not-for-profit consumer organization, committed to promoting awareness about deaf-blind people, and to working towards ensuring educational and employment opportunities, high standards of living, and equal access for all Deaf-Blind Americans. The central focus and purpose of AADB is its national convention.

When: June 13-19, 1998

Where: Central Connecticut State University
New Britain, Connecticut

The theme is **"Deaf-Blind Connection: Expanding Opportunities."** For information, contact:

Elaine Ducharme, Convention Chairperson
TTY: (860) 379-0193 (please type slowly to give her time to read braille connected to TTY)

Tom Peters, Co-chairperson
TTY: (860) 621-6610
Fax: (860) 621-7291
funnytom@megahits.com

We need volunteers for general conference assistance, relief worker, and as support service providers for deaf-blind persons.
Contact
Susan Sjoholm
TTY: (860) 379-0193
110104.2207@compuserve.com

AADB also publishes a quarterly newsletter, *The Deaf-Blind American*. For more information about AADB, or the newsletter, contact:

AADB
814 Thayer Ave, Ste. 302
Silver Spring, MD 20910
TTY: (301) 588-6545
Fax: (301) 588-8705
aadb@erols.com

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Deaf-Blind Perspectives

Volume 5, Issue 3 Spring 1998

Early Identification of Infants who are Deaf-Blind: A Systematic Approach for Early Interventionists

Deborah Chen
Associate Professor, California State University, Northridge

In an ideal world, **all** infants would receive screenings for their vision and hearing with coordinated follow-up services as needed. Indeed, universal infant screening for hearing loss has been recommended nationally (Mauk, Barringer, & Mauk, 1995; National Institutes of Health, 1993); however, few states have implemented this recommendation. Likewise, both the National Academy of Ophthalmology and the National Academy of Optometry have recommended a comprehensive visual examination for all infants (American Academy of Ophthalmology, 1992; American Optometric Association, 1994), but this is not common practice.

As a result, the professionals who work in early intervention programs either as direct service providers or as consultants, play an important role in the early identification of vision impairment and hearing loss. These professionals may include physical therapists, occupational therapists, nurses, speech and language therapists, audiologists, orientation and mobility specialists, psychologists, social workers, and teachers certified in the areas of early childhood special education, vision impairment, hearing loss, deaf-blindness, or severe disabilities, as well as other specialized consultants. An early interventionist is thus any professional who provides direct services to infants (birth through 36 months) with disabilities and their families. Unfortunately, national estimates indicate that more than 95% of states have shortages of **qualified** early intervention personnel particularly in specialization areas, and that approximately 80% of states anticipate that these shortages will continue to the year 2000 (Klein & Campbell, 1990). These statistics indicate that many programs serving infants with severe or multiple disabilities may not have easy access to educational professionals who know how to screen infant vision and hearing. Further, socioeconomic and other conditions may restrict a family's access to such medical services (Halpern, 1993; Lewit, 1992) as audiology, ophthalmology, or optometry. Given this lack, it is imperative that people who work with infants who have disabilities (a) are familiar with the high risk factors and signs associated with vision and/or hearing loss, (b) are skilled in gathering information about the status of an infant's vision and hearing, (c) are familiar with procedures for making referrals to audiologists and ophthalmologists or optometrists, and (d) know how to access the services of consultants or teachers certified in vision impairment, hearing loss, or deaf-blindness.

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Identification of High Risk Factors

Many high risk factors are associated with **both** a visual impairment and a hearing loss as shown in Figure 1. Vision and hearing are such primary avenues for learning that infants who have vision impairments combined with hearing losses should receive specific supports to promote development. In most cases, visual impairment is identified first, so the hearing of these infants must be tested and monitored closely. Because language is developed during infancy, even a slight, transient, or unilateral hearing loss can distort speech input and impede the speech discrimination and comprehension abilities of infants (Kile, Schaffmeyer, & Kuba, 1994; Nozza, 1994). Early interventionists working with infants who have severe disabilities, infants who are visually impaired, and

EC 307524

High Risk Factors Associated with Hearing Loss	High Risk Factors Associated with Visual Impairment
– Family history – Prenatal exposure to maternal infections (toxoplasmosis, syphilis, rubella, cytomegalovirus, herpes) – Prematurity – Hypoxia – Cleft lip and palate – Craniofacial anomalies (malformations of pinna, ear canal, absent philtrum, low hairline) – Hyperbilirubinemia level requiring transfusion – Apgar score of 3 or less at 5 minutes after birth – Prolonged use of ototoxic medications – Prolonged medical ventilation (10 days) – Certain syndromes (e.g., CHARGE, Down, Fetal Alcohol, Goldenhar, Hurler, Norrie, Refsum, Trisomy 13, Waardenburg) – Childhood infections (bacterial meningitis, mumps, measles) – Head trauma – Cerebral palsy – Certain neurodegenerative disorders (e.g., neurofibromatosis, Tay-Sach, Niemann-Pick disease)	– Family history – Prenatal exposure to maternal infections (toxoplasmosis, syphilis, rubella, cytomegalovirus, herpes, chicken pox, HIV) – Abnormal prenatal brain development – Prematurity – Hypoxia – Certain syndromes (e.g., CHARGE, cri du chat, Down ,Fetal Alcohol, Goldenhar, Hurler, Lowe, Marfan, Norrie, Refsum, Trisomy 13) – Other congenital ophthalmological syndromes (optic nerve hypoplasia, Leber's) – Bacterial meningitis – Head trauma – Cerebral palsy – Certain neurodegenerative disorders (e.g.,neurofibromatosis, Tay Sachs)
(Joint Committee on Infant Hearing, 1991; Northern & Downs, 1991)	(Northern & Downs, 1991; Teplin, 1995)

Figure 1. High Risk Factors Associated with Hearing Loss or Visual Impairment in Very Young Children (Chen 1997).

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infants who are deaf or hard of hearing should be aware that certain etiologies are associated with vision impairment and hearing loss.

Children who are developmentally delayed or who have cerebral palsy, and those with Down syndrome have a higher incidence of refractive errors and other ophthalmological problems than nondisabled peers (Capute & Accardo, 1991; Hoon, 1991; Wesson & Maino, 1995). At least 78% of children with Down syndrome have a hearing loss (Northern & Downs, 1991). There are over 70 syndromes in which hearing loss and visual impairment are likely to occur together (Regenbogen & Coscas, 1985). Research also indicates that 42 to 90% of children with severe or profound disabilities have visual impairments (Cress et al., 1981; Jacobson & Janicki, 1985). At least 20% of children who have severe and multiple disabilities have a hearing loss and over 33% of children with hearing loss have an additional disability (Sobsey & Wolf-Schein, 1991). Indeed, infants with severe and multiple disabilities are more likely to have a vision impairment or a hearing loss than any other group of children. They are also likely to require early intervention services to facilitate their learning and development.

A Systematic Approach

Early interventionists play an important role in identifying infants who should receive clinical hearing and vision evaluations. They should review the infant's medical reports, gather information from parents, conduct structured observations of the infant's response to sound and reactions to visual stimuli, and assist parents in obtaining a referral to an audiologist, ophthalmologist or optometrist, and educational services as needed.

Review medical records

With consent of the family and program approval, early interventionists should examine medical reports to identify the etiology of the infant's disability and tests which have been conducted. The following procedures provide a systematic approach:

1. Review the audiological report to identify the types of hearing tests that were conducted, the results, the reliability of the results if indicated in the report, and the recommendations of the audiologist. Was a hearing loss identified? If so, what is the type and degree of loss? Were hearing aids recommended? If so, is the infant wearing them? If not, what is the reason? If hearing aids were not recommended, why not? When was the last hearing test conducted? When should the infant receive another hearing test? Were any recommendations made regarding specific interventions to assist the infant's use of hearing or communication development? How have these recommendations been implemented?
2. Review vision evaluation reports to identify the types of vision tests that were conducted, the results, the reliability of the results if indicated in the report, and the recommendations of the ophthalmologist or optometrist. Was a visual impairment identified? If so, what is the type and severity of the visual impairment? Were corrective lenses recommended? If so, is the infant wearing them? If not, what is the reason? When was the last visual evaluation conducted? When should the infant receive another vision test? Were any recommendations made regarding specific interventions to assist the infant's vision use? How have these recommendations been implemented?

Gather information from families

Frequently, parents are the first to notice that there is "something wrong" with the infant's vision and/or hearing. Early interventionists should find out whether parents have any concerns about their infant's vision or hearing and what they have been told by medical or other professionals about their infant's vision and hearing status.

1. Ask specific questions about the infant's response to sound. What have parents observed about the baby's responses to their voices, household noises, and other sounds? How loud are these sounds? How close do they have to be to the baby to get a response? Does the infant seem to prefer certain sounds? Does the infant demonstrate better responses to sounds presented from particular directions (e.g., to the left, right, above or below the infant's ears)? Does the infant seem to understand any spoken words?
2. Ask specific questions about the infant's reaction to visual stimuli. What have parents noticed about the infant's visual attention and responses to their faces, familiar objects, and bright or shiny toys. What seems to get the infant's visual attention? How close do they have to be to the baby to get a response? Does the infant seem to prefer certain types of visual stimuli? Does the infant demonstrate better visual responses in certain lighting or to stimuli presented at particular positions (e.g., to the left, right, above, or below the infant's eyes)?

Conduct systematic observations

Observe the infant during everyday activities as well as during activities specifically structured to engage the infant's attention to visual and auditory

High Risk Signs of Hearing Loss	High Risk Signs of Visual Impairment
Atypical appearance of the face or ears: – Cleft lip and palate – Malformations of the head or neck – Malformations of the ears including lack of opening at ear canal (atresia) – Frequent earaches or ear infections (otitis media) – Discharge from the ears Atypical listening behaviors: – Has few or inconsistent responses to sounds – Does not seem to listen – Does not respond to caregivers calling his name – Shows a preference for certain types of sounds Atypical vocal development: – Has limited vocalizations – Has abnormalities in voice, intonation, or articulation – Shows a delay in language development Other behaviors: – Pulls on ears or puts hands over ears – Breathes through mouth – Cocks head to one side (Chen, 1990; Gatty, 1996; Fewell, 1983; Joint Committee on Infant Hearing, 1991)	Atypical appearance of the eyes: – Drooping eyelid which obscures the pupil – Obvious abnormalities in the shape or structure of eyes – Absence of a clear, black pupil – Persistent redness of conjunctiva (normally white) – Persistent tearing without crying – High sensitivity to bright light indicated by squinting, closing eyes, or turning head away Unusual eye movements: – Jerky eye movements (nystagmus) – Absence of eyes moving together or sustained eye turn after 4 to 6 months of age Unusual gaze or head positions: – Tilts or turns head in certain positions when looking at an object – Holds object close to eyes – Averts gaze or seems to be looking beside, under, or above the object of focus Absence of visually directed behaviors: – Eye contact by 3 months – Visual fixation or following by 3 months – Accurate reaching for objects by 6 months (Calvello, 1990; Fewell, 1983; Teplin, 1995)

Figure 2. High Risk Signs of a Hearing Loss or Visual Impairment in Very Young Children (Chen 1997).

stimuli. Pay attention to the position of the infant and where the stimuli is presented in relationship to the infant's eyes and ears. Note the distance (12", 3', 5', 10') between the stimuli and the infant. Observe the infant's characteristics, in terms of state, attention and interest.

1. Structured observation: Hearing screening. Are the infant's face and ears typical in appearance? What responses to sound does the infant demonstrate? What types of vocalizations does the infant produce?

What types of sounds elicit the infant's response?

- Type (vocalization, speech, sound toys, music, environmental sounds).
- Intensity (loud, conversational, whisper/soft).
- Duration (length of stimulus).
- Position (of the sound source in relation to the infant's ears).

2. Structured observation: Vision screening. Are the infant's eyes typical in appearance? Are there unusual eye movements?

Does the infant have an atypical gaze or head position? What visual attending behaviors does the infant demonstrate? Does the infant orient towards or reach for a desired person or object? What types of visual stimuli elicit the infant's response?

- Type (familiar face, lights, colored objects, black and white objects, toys, familiar objects).
- Size and background (e.g., Cheerio® on dark placemat, bottle on high chair tray, brown labrador walking across room).
- Duration (length of presentation).
- Position (of the visual stimuli in relation to the infant's eyes).
- Lighting conditions.

Is the stimulus meaningful and familiar or novel? Is the environment quiet and free of distractions? What type of activity was observed? How many trials were conducted? What are your impressions of the infant's responses to visual and auditory stimuli? Look for high risk signs of hearing loss or visual impairment as shown on Figure 2 by observing the infant's appearance; looking and listening behaviors; vocalizations; and eye-hand coordination.

Analyze Findings

The early interventionist should document and analyze the collective findings from the infant's medical reports, information from the family, and from structured observations to determine whether or not clinical tests may be warranted. Findings and observations should be discussed with available program staff such as the nurse, speech and language therapist, and teachers certified in visual impairment, deaf and hard of hearing, or deaf-blind specializations. If the infant responded to visual or auditory stimuli, the team should discuss the type of responses that were observed. For example, responses may be *reflexive or awareness behaviors* (i.e., eye blinks, limb movements, or body startles); *attention or alerting behaviors* (i.e., looking, reaching, searching, smiling); or *discrimination, recognition, or examining behaviors* (i.e., differential responses to auditory and visual stimuli and indicating preferences) (Barraga, 1976; Chen, 1990; Flexer, 1994; Gleason, 1984; Hall & Bailey, 1989; Leuck, Chen & Kekelis, in press; Northern & Downs, 1991). Even the latter set of responses does not ensure that the infant has normal vision and hearing. If the infant demonstrates high risk indicators or signs of vision impairment or hearing loss, if the family has concerns, or if infant responses to visual stimuli or sounds are questionable, then the early interventionist should assist the family in seeking a referral for a vision and/or hearing test. If possible, referral should be obtained to a pediatric audiologist and pediatric ophthalmologist or optometrist who have expertise in evaluating infants—preferably infants who have multiple disabilities.

Conduct Follow-up Services

Once evaluations are completed, families and other members of the early intervention program team should discuss test results and recommendations. It is essential for early intervention professionals to consult and collaborate with other professionals who have expertise in working with infants who are visually impaired, deaf or hard of hearing, or deaf-blind. All professionals involved with the infant should participate as members of a coordinated transdisciplinary team to avoid subjecting families to fragmented services involving multiple professionals.

Educational resources are available for deaf-blind infants and children. Each state has a federally funded deaf-blind project which serves as a valuable resource for early intervention programs and families to obtain technical assistance regarding relevant strategies and other resources. The federal government also sponsors DB-LINK (The National Information Clearinghouse On Children Who Are Deaf-Blind). To locate the deaf-blind project for a particular state and other information resources call DB-LINK (800) 438-9376.

Teachers certified in the areas of vision impairment, hearing loss, or deaf-blindness can explain terminology and diagnoses and suggest environmental adaptations, activity modifications and other specific interventions. For example, families and other professionals may question the terms 'deaf," blind," and "deaf-blind" if the infant reacts to some sounds and visual stimuli. Caregivers may also need information about ways to develop communication with their infants who are deaf-blind. If the infant is diagnosed as having a vision impairment and/or hearing loss, recommendations should be reviewed and families should make decisions regarding their implementation. Specific interventions should then be developed to address the infant's needs. These interventions need to fit within the family's routine and culture. An individualized approach is essential for establishing collaborative relationships with families from diverse cultural and linguistic backgrounds.

Summary

Vision impairment coupled with hearing loss profoundly affects a child's ability to learn. Early identification of vision impairment and hearing loss is the essential first step in making sure that infants who are deaf-blind and their families receive appropriate support and early intervention services. Early interventionists should be aware of high risk factors associated with hearing and vision loss, use a systematic approach to screening, and have knowledge of available medical and educational resources in order to identify and obtain services for deaf-blind infants as early as possible.

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Research-to-Practice Focus: FM Systems For Children Who Are Deaf-Blind

Barbara Franklin, Ph.D.
Megan Jones, M.A.

Public areas such as auditoriums, theaters, and restaurants provide poor acoustical environments for people who have a hearing loss. In such places, echos and reverberations, as well as "background noise," can greatly interfere with a person's ability to hear what someone else is saying, even with the use of a hearing aid. Children who are deaf-blind may face similar difficulties hearing their teachers or peers in the school and classroom. "Assistive listening devices," however, can improve students' abilities to hear others by reducing acoustic problems.

This information sheet provides an overview of assistive listening devices for children who are deaf-blind. It explains what these devices are, describes how they work, considers potential problems and solutions, and reviews current technology. This information sheet is based upon the work of Dr. Barbara Franklin who, with the assistance of Megan Jones, M.A., conducted a federally funded research project entitled "FM Systems with Children who are Deaf-Blind." The project, now in its final year of funding, is being conducted at San Francisco State University.

Types of FM Systems

The most typical assistive listening devices are personal FM systems and FM auditory trainers. Both work by providing the user with a constant "sound pressure level" of the speaker's voice. With a personal FM system, a speaker's voice is sent through the hearing aid(s). The speaker (e.g., teacher) wears a microphone transmitter that sends his or her voice to a receiver. The receiver is attached by a loop or cord to the microphone of the listener's hearing aid(s). With an FM auditory trainer, the speaker similarly wears a microphone transmitter, and his or her voice is sent to a microphone in a receiving unit that the listener wears on the body. The components for either the personal system or the auditory trainer are contained in a rather bulky case, which is placed on the child's chest or back.

New FM System Technology

A newer type of FM receiver is now available which combines the hearing aid and FM system in a single behind-the-ear unit (BTE/FM). This new BTE/FM eliminates the body-worn case, as well as all loops and cords. The unit operates as a hearing aid alone, an FM system alone, or a hearing aid and FM system simultaneously. Several companies have produced these units, including Phonic Ear, AVR Sonnovation (a company in Israel), and Telex. A BTE/FM unit for individuals with severe to profound hearing loss who need to communicate in noisy environments is being jointly developed by Sonnovation and Unitron. The latest advance comes from Phonak, which has developed the world's smallest FM microchip ever designed for spoken communication. The device, called a Microlink, is about one third of an inch and is attached to a plastic boot that slips over the end of the over-the-ear hearing aid.

Considerations for Purchasing an FM System

Several questions might be considered when purchasing an FM system:

- Does the degree of amplification which the FM system provides match the degree of amplification the user needs? A child with a mild hearing loss, for example, might be "overpowered" by a system with a great amount of amplification, while a child with a severe hearing loss will be underserved with a system that does not provide enough amplification.
- How might the sound provided by the FM system change when the system is connected to a child's hearing aid? The addition of a hearing aid to the FM "loop" can alter the nature of the sound provided by the FM unit, which may result in problems.
- Will the child be able to regulate the microphone on the FM receiver or access the on-off switch?
- What is the most effective input mechanism for the individual? In general, earphones are only appropriate for children with little hearing loss who do not use hearing aids. "Teleloop inductors" can be used by most children with a telecoil switch on their hearing aids, but may be less useful for those with more than a moderate hearing loss because the sound signal tends to fade in and out when the user changes head position. Direct audio input cords provide the greatest de-

gree of sound delivery, but they are more delicate than headphones or teleloops—a consideration for younger or very active children.

- Are the new BTE/FM units appropriate for the child? One drawback to this type of unit is that it may have an easily broken external antenna on the hearing aid. Another drawback is that these combined systems do not as yet deliver the same quality of sound as do other FM systems currently on the market.

Potential Problems in FM System Use

Just because a student uses an FM system does not necessarily mean that his or her hearing has improved. If your child or student uses an FM system, you should be aware of several potential problems:

- The microphone might be too close or too far from the speaker's mouth. Six inches from the mouth is optimum placement. Make a fist under the chin and attach the microphone to the clothes at the resulting distance.
- Be careful that the speaker's jewelry and clothing do not cause static.
- A speaker might hold the microphone instead of clipping it onto clothing. Fidgeting with the microphone hand may cause the speech signal to fade in and out.
- Many users lack the basic knowledge to troubleshoot the systems or to operate the more complex units.
- The type of microphone used can have a significant impact on the FM signal. Omni-directional, conference, or environmental microphones are effective where there is little background noise, such as in classroom lectures or small group discussions. On the other hand, they may not be effective in a noisy classroom, cafeteria, or playground. Uni-directional and "boom" microphones are more effective for noisy environments. It is desirable for the child to have a variety of microphones on hand to provide for environmental differences. If only one microphone is to be purchased, the uni-directional type is preferred.

Variations in Settings and Speakers

If the child is in an environment where more than one person is speaking (e.g., group discussions), several microphone arrangements are possible. One option is to pass the transmitter microphone and/or corded receiver microphone around to each person as he or she speaks. Such an arrangement requires anticipation on the part of the group, instructor, and consumer. A speaker may have to wait for the microphone before offering comments. Another option is for a main speaker to paraphrase what other group members say. In a large group, it may be beneficial for the main speaker to retain the transmitter while an assistant paraphrases the comments into the microphone of the child's receiver. A third option, especially helpful when there are two main instructors or speakers, involves the simultaneous use of two FM systems which can provide input into one receiving unit.

Children who have Hearing Loss and Other Disabilities

There are some simple, inexpensive ways to modify FM systems for better access by users who have visual impairments. For children who use braille, braille labels identifying components should be affixed to the system. Large print labels can be used for students with low vision. A rubber band or other tactual cue can be used to help the student distinguish the receiver from the transmitter. Materials such as Hi Marks™, which can be squeezed out of a tube to form a raised line when it hardens, is an excellent labeling tool for indicating volume setting.

The use of a "loop" or sound field system may be less cumbersome than personal receivers for individuals with mobility impairments. But one drawback of the loop option is that the telecoil switch on the child's hearing aid must be turned on and off to access or eliminate the FM signal. It should also be kept in mind that sound field systems do not bring the sound as close to the ear as personal receivers do. A receiver or transmitter can also be strapped to the arm rest of a wheelchair for easy access to sounds. In addition, wheelchairs can now be outfitted with speakers for FM systems on either side of the headrest.

Additional Information

Contact Dr. Barbara Franklin for additional or more specific information about FM systems for children who are deaf-blind. She can be reached at San Francisco State University, Department of Special Edu-

cation, 1600 Holloway Avenue, San Francisco, CA, 94132, e-mail: barbf@sfsu.edu, phone: 415-338-1161. A good general information book on FM usage with children is Flexer, C. (1994). Facilitating Hearing and Listening in Young Children, Singular Publishing Group, San Diego, CA.

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The Universality of the Usher Experience

Ilene Miner, CSW

During the past five years I have had an opportunity to travel and meet people with Usher Syndrome throughout the United States and in many different countries. I believe these experiences have much to offer those of us who do not have Usher Syndrome. If we attend to what is being said, we will learn about the lives, feelings, and thoughts of some extraordinary people. We will also learn ways in which service providers might meet their needs.

Many people have said they clearly remember the first time they met someone else with Usher Syndrome. First of all, they were grateful to learn they were no longer alone. Second, they discovered they have much in common no matter what part of the world they come from. One reason for this is that the "natural history" of either Usher 1 or Usher 2 is similar for people regardless of where they grow up. People with Usher 1 are born profoundly deaf and generally use sign language as their primary mode of communication. People with Usher 2 are born hard-of-hearing and generally use spoken language. In both groups, however, sometime during childhood or adolescence, vision problems become apparent, and the diagnosis of Usher Syndrome is made.

All children grow up internalizing a view of what they will become from those around them. Many times, those with Usher Syndrome grow up without ever meeting another person with Usher. As a result, they may have no idea of what the future holds for them. Sometimes this isolation is by design. Parents may fear that meeting a person with Usher whose vision has started to deteriorate will create despair in their child. They may have received this message from professionals. In some cases, professional advice to place children in inclusive education settings has resulted in the child being removed from the only place in which he or she might have met other children with Usher, such as a deaf day or residential school, or a deaf class in a mainstream school.

The underlying message of never telling a child about Usher or keeping him or her away from other people with Usher is, "What is happening to you is so awful that we, your caretakers, your family, can't even bear to mention it or expose you to it." There is a further message which is strongly disabling, "People who are just like you have nothing to offer you," and by extension, "People like you have nothing to offer."

Many people with Usher Syndrome have told me they have felt "different" for most of their lives. They almost never had the chance to be with someone just like themselves to hash out issues, to share experiences and war stories, to worry, to wonder, to laugh. The following vignettes illustrate the importance of connections between people who have Usher Syndrome. All are situations in which I was personally involved. Names, ages, and gender are changed.

Bob, Lana, and Roberta are teens with Usher. Two of their parents told me not to mention the word "blind" when talking with their children. I agreed because I knew I wouldn't have to, the teens would be discussing the subject themselves. Their discussion follows:

Bob: So, how is your vision?

Lana: Not so good.

Roberta to Bob: How's yours?

Bob: OK so far, I am hoping to make it through college before I go blind. What about you?

Roberta: I am losing mine pretty quickly, so I don't know if I will get through college first.

Lana: How are your parents taking it?

Roberta: Whew, not so good. They get upset so easily that I find I can't discuss it with them.

Gail, a woman of 24 with Usher 1, recounted meeting Fran who also has Usher 1, at a party when they were 18 years old. Neither had ever met anyone else with Usher. Their boyfriends knew each other and introduced them. Soon they were trading "war" stories.

Gail: I was at a party, tripped and spilled a drink all over the hostess.

Fran: I was going into the movies and fell flat on my face.

Gail: I once knocked my drink into my friend's TTY."

When Gail described this, she told me that they laughed so hard that tears were rolling down their faces. Gail described both boyfriends standing and watching in a state of utter disbelief. She said it was the first time she felt safe enough to reveal her feel-

ings of embarrassment and laugh with someone who could really laugh with her and not at her.

These connections can also benefit parents. At a meeting of families of children with Usher, Sara, a mother of two teens with Usher from Europe) approached Bill, who grew up in the USA., and has Usher 1 and an advanced university degree. She told him, "You have given me hope. You have given my life back to me." Sara had never met an adult with Usher Syndrome and had thought her children could never work or be independent.

Jane and Lei have Usher Syndrome, Type 1. Jane grew up in the USA and Lei grew up in Asia. They initially met through the Internet and later had an opportunity to meet in person. They found they had much in common. Both were blind by their late 30s. Each has siblings with Usher, but because their parents never learned sign language, both Jane and Lei lost the ability to communicate directly with their parents when they lost their vision. Both of them use their country's sign language for communication and read and write fluently.

Tom, who grew up in Europe, and Deb, who grew up in the United States, have Usher Type 2. They are 20 years apart in age. Both are hard-of-hearing, and learned sign language in graduate school. Both were mainstreamed and have advanced university degrees. It happens that they also share a profession. Deb has been working for 20 years, and Tom is just starting out.

> **Tom**: When I look at you, I can finally see my future. I didn't know what would happen to me. Could I continue to work? Can I have children? I have never met another person with Usher before.
>
> **Deb**: When I look at you, I see myself as a younger person, but at the same time you are far ahead of where I was at your age.
>
> **Tom**: I get strength from talking to you and seeing how your life has gone.

Kristin who has Usher 1 and is totally blind and I were in Europe where we met Jan, a man in his 60s also with Usher 1 and totally blind. Jan was thrilled to finally meet someone who really understood. Although Jan and Kristin did not share a common sign language, they communicated with ease using pidgin sign.

> **Jan**: I am so depressed since I lost my vision 6 years ago. I think of suicide every day.
>
> **Kristin**: Ah, I went through this too, a serious depression and suicide attempt, but that is over now. It can get better for you.

Kristin and Jan continued to talk and soon they were comparing life stories. Jan left our meeting with a kernel of hope. Many people I have worked with have attempted suicide or thought of suicide. The issue of depression in people with Usher who are isolated needs to be examined.

I met Mara in Europe at a school for the Deaf which has a deaf-blind high school incorporated within it. There were six girls who lived and went to school together. Watching them interact in their dorm, I was struck by their closeness although they had been together only six weeks when I met them. Mara also told me with great animation about the school trip to a deaf-blind youth conference in another country and the thrill of meeting dozens of teens just like themselves. People with Usher of all ages upon arrival for their first time at any large gathering of deaf-blind people have told me, "I feel I have come home." When people meet, what is expressed is the comfort and joy of being among "family." To use Theresa Smith's word, being in a group of people with Usher affords time to be "unmarked." It affords time and a place to just be a person, and not just a person with Usher. People with Usher also learn from and teach each other.

At the European Usher Study Group meeting in Madrid last July, I met with people who have Usher Syndrome from five or six different countries. Despite different backgrounds, different signed languages, and different spoken languages, there was communication every moment. There was excitement and closeness. They discussed issues that included having, caring for, and raising children; needing to change jobs; embarrassment at having to learn mobility skills; delight in socializing with others with Usher; communication issues and role changes at home; difficulty communicating with parents and siblings; episodes of sadness; and concerns about old age.

The need to be validated and to know that one is not alone in the world is universal.

What Can We Professionals Do?

Create More Opportunities for People With Usher To Connect With One Another

Many people with Usher have said they feel isolated and lonely and wish they could get together easily on a regular basis. Some have said they would be happier at work if they could share time with others who also have Usher Syndrome. Students who do not have an opportunity to interact with other students who have Usher often experience isolation. Enclave schools and work sites are solutions to these problems. As the vignettes above demonstrate, being around others with Usher is extremely impor-

tant and positive. We should stop using the label "normalization"as a way to keep people with Usher away from each other in the classroom, and during social and work time. We need to "normalize" having Usher.

It is important to help young people with Usher Syndrome connect with other people who have Usher Syndrome as soon as they are diagnosed. Adults with Usher Syndrome should be the first source of support and information to newly diagnosed families. Teens enjoy asking questions of adults, and adults enjoy sharing their experiences and wisdom. Young people can find role models and heroes; older people can become mentors. These precious moments should be available to all. More opportunities for peer counseling, mentoring programs and large group events should be created. Early and consistent involvement with people of all ages will provide young people and their families with a sense of the future.

Other ways to decrease the isolation and information deprivation experienced by people with Usher Syndrome are to increase the availability of interpreters and support service providers, and to make computers available to all people who are deaf-blind. Through computer networks, information and people from around the world can get in touch with each other.

Become Involved in the Community and Culture of Deaf-Blind People

Professionals should spend more time outside the office setting, interacting with people who have Usher Syndrome. More professionals need to attend national or international conferences planned by and with people who are deaf-blind. It is also important to become fluent in sign language or at least to use an interpreter. People with Usher have told me it makes them angry when professionals don't sign or use an interpreter, don't wear clothing with solid background that contrasts to skin color, and don't convey an attitude of respect.

When working with young people, professionals need to communicate directly with the young person, not just to the parents. Too often young adults have told me that, when they were being interviewed with their parents, no one directed any comments or questions to them. Teens and adults with Usher can tell their own stories. They have the right to be accorded respect and validation that comes with being responsible for their own life stories.

Professionals Don't Have All the Answers

If professionals are to maintain credibility, we must admit we don't have all the answers.

People with Usher Syndrome are the real experts. We must listen to them to find out what they need. The community of people with Usher Syndrome in Seattle is a good example of this. Members of the deaf-blind community in Seattle have been actively involved in developing improved transportation services, setting priorities for the community, consulting to service agencies, teaching in interpreter training programs, and working at the annual deaf-blind camp.

Additionally, there is a need for more people with Usher Syndrome to become professionals themselves. Too few of us speak from experience that is both professional and personal. People with Usher Syndrome would thus play more of a leadership role in the development of the information and services that affect their lives.

Summary

We find great consistency in the stories told by people who have Usher Syndrome. Over and over, we hear the need to be together, to learn from each other, to feel validated and less alone, and to share experiences. People with Usher need what everyone needs—friendship, respect, community, work, support, control of their own lives, and the power to make decisions. If we listen to what people with Usher tell us, the answers will be clear.

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E-mail Discussion Groups

The following listservs provide forums for people who are deaf-blind, their families and friends, and professionals so they may share information via e-mail.

Deaf-Blind Mailing List

To subscribe, send the following command in the body of an e-mail message
`SUBSCRIBE DEAFBLND` *firstname lastname*

Note that "deafblnd" is the correct spelling. Send the e-mail to listserv@tr.wou.edu. All messages are archived at http://www.tr.wou.edu/archives

If you have difficulty subscribing contact Randy Klumph at owner-request@tr.wou.edu.

Usher-List

To subscribe to this electronic discussion group, send an e-mail message to majordomo@farside.cc.misu.nodak.edu Subject category should be left blank for DOS users and filled in as "subscribe" for Windows users. The body of your message should read as follows: subscribe usher-list yourname@your.service.com If you have difficulty subscribing contact Lynne Krumn at aud2@minot.nodak.net

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My Continuing Journey with Usher Syndrome

Winnie Tunison

My name is Winnie Tunison, and I have Usher Syndrome Type I. I was born deaf and became blind ten years ago when I was forty. This was a big disappointment because I had hoped that I would be much older when I lost my sight. My parents learned that I had retinitis pigmentosa when I was eight, but I was never told and didn't find out until I was twenty-nine. I want to write about the feelings I experienced as I went through the stages of vision loss. I hope that my story will help others who read about it.

I have always felt different from other people–as a child, teenager, young adult, and as a deaf-blind woman now. I knew I was a little different from other students in the school for the deaf I attended for 15 years, however, I could not understand why. My peers could do a lot more than I could in sports and in poorly lit places, and they could sign to each other from a long distance. Even though I was well liked by everyone, I was not part of a group of close friends. When I was a teenager, I was not allowed to participate in sports, but I was never told why and I was too scared to ask. I had never heard of Usher Syndrome, so I assumed that I was nearsighted.

I married at twenty instead of going to Gallaudet University. I think this was partly because I felt it would be easier to be a married woman than a student. If I went to college, my "differentness" would stand out again, and I didn't want to be different.

During the early years of my marriage, I participated in a Deaf Women's Club once every month. During this time, my feeling of being different from my friends became stronger. It was hard to follow the many conversations going on between my friends, so I only watched one person at a time, and missed out on other conversations. I tried to ignore the fact that I was missing so much, but it became more difficult. I was beginning to feel badly about not being able to keep up. My friends tried to help by taking turns telling me what the others were discussing. Although this was thoughtful, it embarrassed me.

As my vision continued to deteriorate, I found peace at home with my family. I also enjoyed having friends over to visit, but only one or two at one time. Having fewer people meant I could control the flow of the discussion more easily and I could control the lighting , so I could see more clearly.

Early on, when my vision was deteriorating, I attended a convention of the American Association of the Deaf-Blind. At first, I was uneasy among so many deaf-blind people because seeing and being with them reminded me that I would be like them someday. I was also uncomfortable socializing with hearing people because I could no longer communicate freely with them, and with deaf people because they signed too fast for me to read. These issues made me feel very different from each of the groups. I belonged nowhere.

Seeing fewer and fewer people led me to become isolated and lonely. I knew I could not depend on my husband and daughters for entertainment. The isolation and depression I felt caused insomnia. This led me to attempt suicide by taking an overdose of medication. I was jealous of everyone and their independence and freedom. I felt unloved, unworthy, and unneeded. Of course I knew that my family and close friends loved and cared about me, but it was not enough. I needed to be more sociable, and meeting people and doing things, but I couldn't.

After extensive counseling and therapy, I regained positive feelings about myself. Instead of bottling-up my feelings, I disclosed how I felt about becoming blind, and how I felt about life before and after blindness. I found that revealing myself was a great way to educate people about deaf-blindness. I started to make many friends, hearing, deaf, and deaf-blind.

Now that I am blind and after ten years of socializing with deaf-blind folks, I am much closer to them. Deaf-blind people have a very strong bond because of their dual disabilities. Although we are few in number and often live far apart, when we meet each other, whether old friends or strangers, we are very happy. I am also now happy among the deaf again. In spite of my blindness, I do not feel much difference between us. Talking with hearing people is still a challenge, but I feel wholly normal talking with hearing people with the help of an interpreter and I talk with my hearing relatives by using my Telebraille. It is a wonderful feeling to be able to talk with everyone once again.

I have spent a long time sorting out my feelings about my blindness and my life. I went through times of despair and depression. My feeling of being so different from other people kept me isolated. I remember all these feelings and know they are a part of me. But I am in a better place now. I have come to feel better about myself and my life and I have formed strong connections with many other people. I hope other deaf-blind people see and hear my story and know that they are not alone.

Winnie Tunison is a junior at Gallaudet University. She can be reached via e-mail at 11wtunison@gallua.gallaudet.edu

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Notes From AADB

Sharing My Perspectives

Harry C. Anderson

As a deaf-blind consumer and president of the American Association of the Deaf-Blind (AADB), I wish to share with you my fervor, determination, modesty and enthusiasm. As I have traveled as a keynote speaker in workshops on deaf-blindness and as the spokesperson for AADB, I have witnessed professionals and parents become inspired and interested in the needs of deaf-blind children. I have seen children learn and gain self-esteem. And I have seen communities gain insight into the needs of the deaf-blind community and have found that they are eager to provide services.

My dream is to see children, youth and young adults who are deaf-blind blossom and become more visible and recognized by people in all walks of life. I also aim to increase awareness of AADB and our staunch advocacy for accessible services, independence, employment and above all acceptable attitudes and the respect that we deserve.

I believe in miracles, but I cannot do the miracle alone, spreading great words about the deaf-blind community to the huge mass of Americans in our country. Deaf blind consumers, parents of deaf-blind children, advocates, interpreters, and special service providers (SSPs) for deaf-blind people need to reach out and touch the hearts and minds of neighbors, civic organizations, community leaders and state legislators, as well as Congress. It is essential that we promote a positive panoramic view of the deaf-blind community, not only during Helen Keller Awareness Week, but all year round. It is a challenge for all of us. Making a change is a challenge, not a fear. We must all work for the common good. I urge you to become assertive and educate the public.

We all share something in common in our daily lives. It is important for us to tear down the barriers we encounter in society and face the issues that interfere with our children's education, independence, and employment. We must strive to improve quality of life by working on the social complexities within our society.

I agree with this quote from the book, Getting the Best Out of Yourself and Others:

> *"We live in a time of paradox, contradiction, opportunity, and above all, change. To the fearful, change is threatening because they worry that things may get worse. To the hopeful, change is encouraging because they feel things may get better. For those who have confidence in themselves, change is a stimulus because they believe one person can make a difference and influence what goes on around them. These people are the doers and motivators."*

How do we make a difference? Be hopeful and confident doers and motivators! Where there is a beacon of hope and optimism, there is time and space for the spirit of making a difference. Where there is a beacon of hope and optimism, there is a will to push for the changes necessary to make parents, professionals, and deaf-blind consumers more active and stronger in the 21st century. We need to make a commitment to the growth of better services to meet the needs of deaf-blind people and to changes necessary for quality of life. We need to make a difference in society.

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For Your Library

Collaborative Teams for Students with Severe Disabilities: Integrating Therapy and Educational Services.

Rainforth, Beverly;York-Barr, Jennifer. Baltimore: Paul H. Brookes Publishing Co., 1997.

For parents of children with severe disabilities and professionals who provide services to these students, this book addresses issues that team members encounter as they work to collaborate with one another. Outlines principles, practices, and procedures for providing related services as integral components of special education programs for students with severe disabilities. Offers guidance on assessment, curriculum development, and instruction. Suggests processes for identifying team members, scheduling, developing IEP's, co-teaching, conducting team meetings, assuming multiple roles, addressing issues as a group, making group decisions, resolving professional differences, and communicating with parents. Paul H. Brookes Publishing Co., (800) 638-3775. Price $35.00

XII Deafblind International (DBI) World Conference

Lisbon, Portugal

July 20-25 1999

The conference theme is "Developing Through Relationships: Celebrating Achievement." There will be four subthemes:

- Relationships between congenitally deafblind children and young deafblind adults and sighted hearing people;
- Relationships between/among deafblind people;
- Relationships between families and professionals;
- Relationships across borders.

Call for Papers

All participants willing to present a paper at the Conference are invited to send an abstract of about ten to fifteen lines by September 30, 1998 to:

XII World Conference of DbI
Planning Committee
Casa Pia de Lisboa / CAACF
Av. do Restelo, 1 1400 Lisboa
Portugal

Tel. 351..1. 362 00 06 Fax: 363 34 48

E-mail: np28ze@mail.telepac.pt

The committee will give priority to presentations directly related to the main themes of the conference, but will also consider papers addressing other issues concerned with the education and welfare of deafblind children and adults.

Foundations of Orientation and Mobility, (2nd ed).

Blasch, Bruce B. (Ed.);Wiener, William R. (Ed.);Welsh, Richard L. (Ed.) New York, NY: AFB Press, 1997.

This new edition offers contributions from more than 30 subject experts and includes an international perspective, as well as expanded contents on state-of-the-art research in low vision, aging, multiple disabilities, accessibility, program design, and adaptive technology. Chapters are divided into

four areas: human systems, mobility systems, the learner, and the profession. One chapter is devoted to orientation and mobility for people who are deaf-blind. AFB Press, (800) 232-3044. Price $68.95.

Including Deafblind Students: Report from a National Task Force

Goetz, Lori, Ph.D. San Francisco: California Research Institute, 1997.

This manual is based on the work of a federally funded, model demonstration project, "Full Inclusion Project for Students who are Deafblind." The project developed a national task force that included parents, educators, technical assistance providers, and researchers, to address the concerns, challenges, and successes of including deaf-blind students full-time in general education classrooms. The manual can be ordered from California Research Institute, 612 Font Blvd., San Francisco, CA 94132, for $15.00, postage included. Checks should be made payable to San Francisco State University Foundation, Inc.

Instructional Strategies for Braille Literacy

Wormsley, Diane P. (Ed.); D'Andrea, Frances Mary (Ed.) American Foundation for the Blind. NY: AFB Press, 1997.

Offers instructors specific, practical strategies for teaching braille reading and writing. AFB Press, (800) 232-3044. Price $38.95.

Negotiating the Special Education Maze: A Guide for Parents and Teachers

Anderson, Winifred; Chitwood, Stephen; Hayden, Deidre. Bethesda, MD: Woodbine House, 1997.

Explains provisions of the Individuals with Disabilities Education Act (IDEA) in easy-to understand language. New chapters have been added to the previous edition about early intervention and nondiscrimination protection (alternative strategies for using the ADA and Section 504 of the Rehabilitation Act to obtain services for children who don't qualify for special education under IDEA). Also included are numerous charts and checklists, as well as listings of parent groups, state agencies, and disability organizations and hotlines. Woodbine House, (800) 843-7323. Price $16.95.

Self-Determination Across the Life Span: Independence and Choice for People with Disabilities

Sands, Deanna J. (Ed.); Wehmeyer, Michael L. (Ed.) Baltimore, MD: Paul H. Brookes Publishing Co., 1996.

A collection of articles exploring the theoretical, developmental and practical aspects of decision making. It is written by adults with disabilities, parents of children with disabilities, and professionals working in the field. Offers suggestions on how to encourage the growth of self-esteem, incorporate self-determination skills into educational programs, begin skill training in the home, promote self-determination throughout the life span, and evaluate the progress of skill acquisition. Paul H. Brookes Publishing Co., (800) 638-3775. Price $35.00.

Teaching Self-Determination to Students with Disabilities: Basic Skills for Successful Transition

Wehmeyer, Michael; Agran, Martin; Hughes, Carolyn. Baltimore, MD: Paul H. Brookes Publishing Co., 1998.

Provides instructional methods for teaching basic self-determination skills to students with disabilities. Designed to assist teachers in meeting IDEA requirements and planning transition programs according to student preferences. Field tested, hands-on activities provide a variety of ways to promote autonomous behavior and help students learn specific skills including decision making, problem solving, self-advocacy, self-management, self-awareness, goal setting, and assertiveness. Paul H. Brookes Publishing Co., (800) 638-3775. Price $34.95.

Workshop Proceedings of the 1997 National Conference on Deafblindness: The Individual in a Changing Society

Washington, DC June 6-9, 1997, Washington, D.C.: Hilton/Perkins Program, 1997.

Contains more than 60 papers from the conference workshops. To order, contact Vhristine Toney, Hilton/Perkins Program, Perkins School for the Blind, 175 N. Beacon St, Watertown, MA 02712, (617) 972-7228. Price $23.00.

You and Me - Social Connections: Volume Four (includes Parts 4 & 5).

Teaching Research Division, Western Oregon University. Monmouth, OR: Teaching Research, You and Me, 1997.

The fourth and final video of the four volume, five part video series that describes the education of a child who is deaf-blind. The series portrays Riley Ford, who is totally blind and has a profound hearing loss. Volume four contains Parts 4 & 5 and describes the importance of movement and mobility in building social connections for a child who is deaf-blind. This video and all other videos in the series may be ordered from Teaching Research, Western Oregon University, 345 N. Monmouth Ave., Monmouth, OR 97361, (503) 838-8792; TTY (503) 838-8821; Fax (503) 838-8150. Price $15. Video with open captioning are available upon request.

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